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Raune, David John

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Psychosocial Stress and the First Episode of Psychosis

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2001

ABSTRACT

The first episode of psychosis is currently attracting a great deal of international attention in the field of mental health. This is because of the unique theoretical, methodological and clinical advantages that it holds for the study and treatment of psychosis. Psychosocial stress appears to exert a powerful influence both on the course of psychosis and on the well being of informal carers. However, little is known about its role at the first episode.

This project included three studies. The first study aimed to test an aetiological role for stressful events at the first episode. Forty-one patients were included and, consistent with the study hypothesis, independent events of marked/moderate severity clustered in the final three months before onset compared to the preceding nine months. The second study aimed to test if intrusive events would predict the development of persecutory delusions. Thirty-four patients who had a persecutory theme were compared with five patients who did not have this theme. Results were not statistically significant, but they are interesting enough to warrant a future replication using a larger non-persecutory comparison group. The third study aimed to test the validity of a carer appraisal model of expressed emotion (EE) at the first episode, and to compare it with the ability of illness-related factors to predict EE status. Forty-six carers and patients were divided into groups of Low and High EE. Results showed that carer's appraisal was associated with EE whereas illness factors were not.

The theoretical implications of the results are discussed with reference to stress-vulnerability frameworks of psychosis, models of delusions, and models of EE. The clinical implications are discussed with reference to early intervention to ameliorate the deleterious effects of early psychosocial stress on patients and carers. Future research directions are identified for psychosocial stress in psychosis.

ACKNOWLEDGEMENTS

I would like to thank my supervisors Elizabeth Kuipers and Paul Bebbington for their guidance. Elizabeth, in particular for advice on the carer side of the project, and Paul in particular for his advice on the life event side of the project. I would like to thank Marcia Scazufca for her EE advice before the start of the project, and Nick Troop for advice on coping instruments. For training me in the use of the LEDS2, and for her continued help afterwards, I would like to thank Tirril Harris. I also thank Christine Vaughn for training me in the use of the CFI and for advice on the EE results, Sophia Rabe for statistical help, Ruth Williams for general advice and Jeffrey Gray for his helpfulness.

This project could not have been completed without the co-operation of the staff in the twenty six wards and community centres across south London from which participants were recruited. It also could not have been completed without the patients or carers who were willing to reveal in detail their recent stressful experiences. I therefore thank both groups. I also thank Kathy Greenwood for her co-work in recruiting participants.

I would like to thank friends and colleagues who have passed through or are still at the IOP, especially the Social Psychiatry Section, where I was based during the project. I would like to thank Julian Leff both for allowing me to stay in the section and for his advice on the preliminary EE results. Thanks are also due to Yvonne Waters for all her practical and other help. I thank the Medical Research Council for funding the studentship. Finally, I would like to thank my partner Patricia Hay for all her help and support.

STATEMENT OF AUTHORSHIP

As the author of this thesis, under the supervision of Professor Elizabeth Kuipers and Professor Paul Bebbington, I carried out all stages of the research. This comprised the planning of the study, data collection, data analysis and the writing of this thesis. The identification of patient participants was done in collaboration with Katherine Greenwood, Dr. Karena Meehan and Dr. Paul Fearon.

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Chapter 1:

Introduction to Psychosocial Stress and the First Episode of Psychosis

1.1 INTRODUCTION

The first episode of psychosis is currently attracting a great deal of international attention in the field of mental health (e.g. McGorry & Jackson, 1999; Birchwood, Fowler & Jackson, 2000). This is because of the many theoretical, methodological and clinical advantages that it holds for the study and treatment of psychosis. Theoretically, the first episode affords the only opportunity of testing theories of the aetiology of psychosis without a range of confounding influences. Clinically, it is crucial to a growing 'early intervention for psychosis' paradigm. The first episode may be a key part of a critical period in which early intervention could lead to a substantial improvement in the long-term trajectory of the illness (e.g. Birchwood, 1999). Understanding the first episode might even lead to the prevention of some new cases of psychosis (e.g. McGorry, 1998).

The number of people in the United Kingdom (U.K.) each year who develop first episode psychosis is not known, but it is likely to be in the region of 7,000¹ (Castle, Wessely, Van Os & Murray, 1998, p.89; Office For National Statistics, 1998). The first U.K. National Survey of Psychiatric Morbidity calculated that there were about 270,000 psychosis sufferers and this is probably an underestimate (Bebbington et al., 1999). Striking at a relatively young age, generally during the critical developmental phase of adolescence or early adulthood, it often severely interferes with an individual's psychological and social development, and their relationship with their family (McGorry, 1998; Harrop & Trower, 2001; Menezes & Milovan, 2000). There is no definitive estimate of the number of relatives involved in the care of adults with psychosis (Kuipers, 1993). However, a reasonably representative nation-wide sample of

¹ The study by Castle et al. found that the incidence of schizophrenia, the most common psychosis, was 12.1 / 100,000. Using the 1998 U.K. population estimate of 59, 236, 522, this yields a figure of 7,168. The figure for all psychosis would be higher. One caveat is that an inner city sample was used, which tends to inflate the rate, but in the absence of a true figure, 7,000 new episodes of psychosis per year is a reasonable *estimate*.

patients with schizophrenia suggests that nationally about 41% live with their families (Dalton, Bell, Thompson & Wager, 1998). The minimum number of informal carers who live with a psychosis patient is in the region of 110,700 (41% of 270,000). This figure is likely to be much higher given that more than one carer often lives with a sufferer. Moreover, if informal carers who do not live with patients are added, the number is increased further. The extensive burden carers experience has long been known (e.g. Hoenig & Hamilton, 1966; Grad & Sainsbury, 1968) and more recent studies confirm this (e.g. Cornwall & Scott 1996; Szmukler, Wykes & Parkman 1998; Magliano, et al., 1998a). Therefore, in the U.K. there may be more than 400,000 people who are either attempting to cope with their own psychotic illness or are caring for someone with psychosis. This appears to represent a significant public health problem. The overall direct and indirect costs of psychosis appear very high, given the number of cases involved and the long duration of the illness (e.g. Knapp, 1997; Davies & Drummond, 1994; McGorry, 1998).

Psychosocial stress is one factor which seems to influence the expression of psychotic symptoms. Research into the influence of two types of psychosocial stressor, Expressed Emotion (EE) and stressful life events, has led to important theoretical and clinical advances in the field of psychosis. The government policy of community care (e.g. the NHS and Community Care Act, 1990) has meant that patients with psychosis are now exposed to a much wider array of psychosocial stresses and at an earlier phase of the illness. It also means that informal carers have increasingly assumed the burden, from the first episode onwards (e.g. Gleeson, Jackson, Stavely & Burnett, 1999). Along with these social changes, the increased insistence on 'evidence-based medicine' has meant that greater emphasis is now placed upon empirically supported interventions (e.g. Roth & Fonagy, 1996). However, relatively little is known about stressful life events and EE at the first episode of psychosis. This is despite their potential role in informing early individual and family interventions. This thesis therefore will attempt to extend what is known about stressful life events and EE during the first episode of psychosis.

1.2 PSYCHOSIS

1.2.1 The Concept of Psychosis

The concept of psychosis covers a range of diagnoses, including delusional disorders, schizoaffective disorders and affective psychosis, although the most common psychosis is schizophrenia (ICD10, WHO 1992). Early pioneers of the schizophrenia concept include Kraepelin (as discussed by Sass, 1987), Bleuler (1911/1950) and Schneider (1959). Delusions and auditory hallucinations are the two most common and important defining features of the psychosis categories of ICD10. However, many people now view these categories as lacking in reliability and, more particularly, in validity (e.g. Bentall, 1993; Boyle, 1990).

In attempting to re-classify psychosis, some studies have applied factor analysis to the symptoms. Some studies have concluded there are two dimensions of schizophrenia, positive and negative (Crow, 1980; Andreason & Olsen, 1982). Positive symptoms include such phenomena as delusions and hallucinations, while negative symptoms include such phenomena as poverty of speech, social and emotional withdrawal and blunted affect. Other studies have found three dimensions, comprising positive symptoms, negative symptoms and disorganised thinking and behaviour (Liddle, 1987). Still other studies found four or even five factors (Peralta, Cuesta & Deleon, 1994; Lindenmayer, Bernstein-Hyman, Grochowski & Bark, 1995). McGorry, Bell, Dudgeon & Jackson (1998) included a full range of functional psychoses in a large (N=509) first-episode sample and found four robust and clinically valid factors. These comprised depression; mania; a blend of negative, catatonic motor and disorganisation symptoms; and a combination of Schneiderian first-rank symptoms with other delusions and hallucinations. Perhaps the most interesting finding was that disorganisation did not form a clinically distinct dimension of psychopathology in first episode psychosis. This highlights the important point that symptoms evolve over time, and it is necessary to study all phases of psychosis for a complete understanding of the disorder.

1.2.2 The Course of Psychosis

In the course of psychosis, it is now clear that signs can appear well before the onset of typical symptoms. People who develop psychosis may exhibit differences in childhood (e.g. Davies, Russell, Jones & Murray, 1998), pre-morbid social under-achievement (e.g. Jones et al., 1993;

Morris & Macpherson 2001), and pre morbid behavioural and intellectual measures (Davidson, Reichenberg & Rabinowitz, 1999). They may also have previously experienced “at risk” states of altered mental functioning (McGorry & Singh 1995) and a prodromal period (e.g. Yung & McGorry, 1996). Indeed, prodromal periods may average more than two years (e.g. Loebel, Lieberman, Alvir, Mayerhoff, Geisler & Szymanski 1992; Beiser, Erickson, Fleming & Iacono, 1993), possibly even five years (Hafner, 2000). The speed of onset of the first episode can occur on a continuum from insidious to acute. Onset is usually defined as the first expression of psychotic symptoms, such as delusions or hallucinations, although some studies define it as the onset of prodromal symptoms (Keshevan & Schooler, 1992). The short-term course of psychosis shows nearly 60% relapse within two years (Ram, Bromet & Eaton, 1992). The long term outcome of psychosis can be summarised by saying that about a quarter to one third have either a single episode or multiple episodes with little residual symptoms (Birchwood, Todd & Jackson, (1998). The remainder have multiple episodes with varying and often increasing impairment over time.

1.2.3 The Aetiology of Psychosis

The aetiology of psychosis is unclear. Speaking about the aetiology of schizophrenia, Bentall (1993, p.223) states: “it is no exaggeration to say that every variable known to influence human behaviour has at one time or another been identified as a potential cause”. There are possible contributions from genetics (e.g. Murray & McGuffin, 1993), viruses (e.g. McGraph & Murray, 1995), abnormal neurodevelopment (e.g. Murray, 1987) neurotransmitter irregularities (see Frangou & Murray, 1996, pp.25-27), pregnancy and birth complications (e.g. McNeil, 1995), drug use (e.g. Cantwell et al., 1999) and stress. Even monozygotic twins have only about a 50% concordance rate for schizophrenia and dizygotic twins about 15% (e.g. Prescott & Gottesman, 1993), leaving much variance unexplained.

1.2.4 Frameworks and General Theories of Psychosis

A major conceptual advance to thinking about psychosis was the introduction of a stress-vulnerability framework, most clearly framed by Zubin and Spring (1977). This postulates that psychosis is the product of multiple interacting biological, psychological and social factors. Nuechterlein and colleagues have developed a comprehensive stress-vulnerability framework for psychosis (e.g. Nuechterlein, et. al., 1994) combining both vulnerability (e.g. dopaminergic

dysfunctions, schizotypal traits) and protective factors (e.g. anti-psychotic medication, social support). Another conceptual advance has been to view psychosis on a continuum with normality, a view supported by considerable evidence (Strauss, 1969; Claridge & Chappa, 1973; Tien, 1991; Peters, Day, McKenna & Orbach, 1999; Van Os, & Marcelis, 1999; McGovern & Turkington, 2001). At a psychological level of explanation a few single-theories of psychosis, most notably of schizophrenia, have been developed. The two most well developed are Frith (1992) who argues for a meta-representation deficit, and Hemsley (1994) who posits a failure to relate current sensory input to stored regularities. Both have empirical support.

1.2.5 The Single Symptom Approach and the Person Model of Psychotic Symptoms:

Application to Themes in Delusions

In contrast to the 'grand unified theory approach' to psychosis, recent progress at a psychological level is now coming from research aiming to explain single symptoms. Persons (1986) discusses the advantages of this approach. It has been applied successfully to one of the dependent variables in the present study, namely delusions (e.g. Garety & Hemsley, 1994; Chadwick & Birchwood, 1994). Garety, Kuipers, Fowler, Freeman and Bebbington (2001) propose a model of the positive symptoms of psychosis which includes a role for psychosocial stress. The model posits a central role for both cognitive and emotional factors, placing particular emphasis on the person's decision to form an external attribution to explain their symptoms. Another advance has been the development of a person model of psychotic symptoms. This seeks to understand psychosis in the context of a person's life history and current attempts to make sense of the psychosis (Chadwick, Birchwood & Trower, 1996). The single symptom approach and the person model have been combined and used successfully to study the *themes* found in delusions (e.g. Bentall, Kinderman & Kaney, 1994). One of the most common is a persecutory theme, but grandiose, reference and depressive are also prevalent (Spitzer, 1992). Themes are cognitive-affective structures and processes of meaning. They reflect a particular cognitive-affective meaning or schema that an individual uses to organise their relationship to self and the world (Lebowitz & Newman, 1996). The themes found in psychosis are important because they may indicate something about individual stress-vulnerability to psychosis (Hingley, 1992), and are a major source of consequent psychopathology (e.g. Soppitt & Birchwood, 1997; Fowler, Garety & Kuipers, 1995).

However, whilst there has been some progress in understanding the maintenance of themes (e.g. Freeman & Garety, 1999) their causation still currently remains unclear. Yet improvements in therapy for psychosis may well depend on a greater understanding of the mechanisms underlying psychotic symptoms (Fowler et al., 1995). In particular, studying themes at the first episode may reveal clues about causation which disappear later in the course.

1.3 PSYCHOSOCIAL STRESS

The dominant conceptualisation of stress is, at present, interactional. This defines stress only in the context of its likely meaning to a person (Lazarus & Folkman, 1984). Lazarus and Folkman define stress as a relationship between individuals and their environment where they appraise their environment as relevant to their well-being, but which taxes or exceeds their coping resources. Expressed Emotion and stressful life events are psychosocial stressors because they refer to a relationship between individuals and their external environment. Although there are many forms of psychosocial stress (e.g. Wheaton, 1996), the two most studied in the field of psychosis have been events and EE.

1.3.1 Stressful Life Events

Life events are situations or occurrences that entail a discrete, observable and significant change in personal circumstances (Castine, Meador-Woodruff & Dalack, 1998). The dominant methodology for measuring the stressfulness of an event has been that of Brown and Harris (1989). In line with Lazarus and Folkman (1984), they have used an interactionist approach to measuring events. Brown and Harris developed the instrument that is seen as the gold standard in the area, the LEDS2 (1989). It is a semi-structured interview in which the researcher (and sometimes a panel) rate the stressfulness of an event. In doing so, the researcher considers both objective attributes of the event and contextual factors in order to judge how 'threatening' (stressful) an average person in that situation would find that event. The concept of 'threat' comprehensively amalgamates person, event and situational factors and has become the dominant operationalisation of stress in the life event literature. An important advance has been the development of narrower stress concepts to measure events such as 'intrusiveness' (unwanted boundary-breaking control by another) 'danger' (the possibility of a future stress), 'loss', and 'humiliation' (loss of social self-esteem). These permit more specific hypotheses

about the possible influence of stress. Events do commonly occur before the first episode (e.g. Day et al., 1987), but methodological weaknesses mean that replication without the limitations is required. There are also some interesting questions still unanswered, such as how far back events might exert an effect, how severe events are at the first episode and whether the independence of an event plays any role in onset.

1.3.2 Expressed Emotion

Expressed Emotion represents aspects of the quality of the relationship between carers and the person cared for, viewed through the appraisal of the carer (Scazufca & Kuipers, 1996). It is rated from vocal and verbal information obtained by audio-taping the semi-structured Camberwell Family Interview (CFI - Vaughn and Leff, 1976b). From this, five scales are derived. A critical comment (CC) is a statement that, by the manner in which it is expressed, constitutes an unfavourable comment upon the behaviour of the person to whom it refers. Hostility (H) refers to a criticism which attacks a person for what they are, rather than for what they do: negative feeling is generalised in such a way that it is expressed against the person rather than against particular behaviours or attributes. Emotional over-involvement (EOI) comprises elements of over-protection, self-sacrifice, over-devotion, and exaggerated emotional responses reported or displayed at interview. A positive remark (PR) is a statement which expresses praise, approval or appreciation of the behaviour or personality of the person to whom it refers. Warmth (W) is rated according to the degree of enthusiasm, interest, empathy, sympathy and concern shown for the patient. CC and PR are rated by means of frequency counts, while H, W and EOI are given a global rating. A person is defined as High EE if they score six or more critical comments, display any hostility or score three or more on EOI during the CFI. Information on the reliability and validity of the CFI appears in the Method section. The genesis of High EE and its components (CC, H and EOI) is not known, but there is increasing evidence (discussed in Chapter 4) that carers appraisal may hold the key, particularly perhaps their appraisal at the start of the illness.

1.3.3 Psychosocial Stress Research in Psychosis Has Led to Psychosocial Treatments

Research into EE and stressful life events has contributed to the development of new psychological treatments for psychosis. All include the aim of reducing the deleterious effects of stress on the patient. Many reviews have concluded that family interventions have been

effective at lowering relapse rates (Mueser & Bond, 2000; Pharoah, Mari, & Streiner, 2001; Tarrier, Yusupoff, & Kinney, 1998; Huxley, Rendall & Sederer, 2000; Dixon, Adams & Lucksted, 2000; Bustillo, Lauriello, Horan & Keith, 2001; Walz et al., 2001). However, controversy exists as to how much of the effect is due to increased patient medication compliance (Pharoah et al., 1999). Many recent reviews about individual CBT aimed at lowering psychotic symptomatology have concluded that it is an effective treatment (e.g. Birchwood, 1999a; Dickerson, 2000; Brenner & Pfammatter, 2000; Garety, Fowler & Kuipers, 2000; Gould, Mueser, Bolton, Mays & Goff, 2001; Rector, 2001; Cormac, Mota & Campbell, 2001). There is now interest in applying psychological interventions at the first episode of psychosis.

1.4 EARLY INTERVENTION FOR PSYCHOSIS

Early intervention for psychosis is a third paradigm of intervention: an addition to the acute and rehabilitation paradigms, which have dominated for the last 100 years (Jackson & Birchwood, 1996). Birchwood, McGorry & Jackson (1997) state that early intervention comprises three main components. First, early detection; for example identifying people in a prodromal phase of psychosis by educating G.P.'s and the general public about psychosis. Secondly, early treatment. Thirdly, intervention during a 'critical period' which aims to lower the early relapse rate, promote early social recovery, speed recovery from acute psychosis and manage treatment resistance.

The critical period hypothesis, and therefore of early intervention, is supported by an association between a longer duration of untreated psychosis (DUP) and poorer outcome, although the association is complex because of factors that might lead to both (Verdoux, Liraud, Bergey, Assens, Abalan & Van Os, 2001; Norman & Malla 2001). The early (untreated) course of psychosis involves deterioration then a plateau after about two years, which predicts later outcome. There was an improved outcome in patients in developing countries even 10 years after the first episode (Thara, Henrietta, Joseph, Rajkumar & Eaton, 1994). Both these findings suggest that early intervention may alter the illness trajectory. It might also be warranted simply because the rate of suicide is higher than later in the course (Westermeyer, Harrow & Marengo, 1991). If the early phase really is formative in its effect on

the course of psychosis, then psychosocial stress before onset (e.g. life events) and soon after (e.g. expressed emotion) might be particularly damaging to the individual.

A few early intervention for psychosis studies have now been reported. With medication studies, Wyatt, Green & Tuma, (1997) found that early neuroleptic treatment of schizophrenia patients predicted a better level of functioning six to seven years after discharge. With respect to early family intervention, Gleeson et al. (1999) reviewed five studies, concluding that evidence for effectiveness is mixed and weakened by methodological inadequacies of some studies. Concerning individual CBT, there is now some evidence that it is able to improve coping (Jackson et al., 1998), and the regulation of emotions (Hodel, Brenner, Merlo & Teuber, 1998), and lower psychotic symptoms (Haddock, Tarrier, Morrison, Hopkins, Drake & Lewis, 1999). The only published multi-modal study at the first episode, involving the full range of biological psychological and social interventions, is apparently that of McGorry, Edwards, Mihalopoulos, Harrigan & Jackson (1996). Using a historical comparison group (before their early intervention service began) they report better outcomes at a one year follow-up for first episode patients who received the new service. Carbone, Harrigan, McGorry, Curry & Elkins (1999) later found that only patients treated within six months of onset demonstrated significantly the improved outcomes.

1.5 EXTENDING WHAT IS KNOWN ABOUT PSYCHOSOCIAL STRESS AT THE FIRST EPISODE OF PSYCHOSIS

This thesis has three main aims: The first is to test whether stressful events are clustered before onset. A significant clustering would be predicted if events played a role in the expression of the first episode. Design features will be used which address both the methodological shortcomings of previous studies and also provide data on unanswered questions about event timing, severity, independence and event type. This could have theoretical implications for models of psychosis and early stress-management intervention. The second main aim is to discover if a link can be found between event type and delusional theme. Knowledge of such a link would have implications for theoretical models of delusions and for CBT to reduce them. The third aim is to test whether carers' appraisal at the first episode of psychosis will both be associated with their EE status (High versus Low) and also be a better predictor than patient illness-related factors. Such information might contribute to stress-vulnerability frameworks of

psychosis and provide guidance to early family interventions. Chapter 2 discusses the role of stressful events at the first episode. Chapter 3 explores a possible role for psychosocial stress on delusional theme. Chapter 4 discusses EE, particularly its genesis.

1.6 SUMMARY OF CHAPTER 1

The first episode of psychosis offers many theoretical, methodological and clinical advantages for research and treatment into psychosis. In the UK there may be at least 7,000 new cases of first episode psychosis per year, 270,000 sufferers, and 110,000 carers. This makes it a significant public health problem. Psychosocial stress in the form of stressful life events and Expressed Emotion (EE) appear to influence the expression of psychotic symptoms. Yet the government policy of community care means that psychosis patients may be exposed to a wider array of psychosocial stresses even at an early stage of the illness. It also means that informal carers have increasingly taken on the strain and burden at an earlier stage.

The concept, course and aetiology of psychosis were discussed and the usefulness of a stress-vulnerability framework in understanding the illness was noted. The study of individual symptoms and the person model of psychosis has led to recent progress in understanding the themes in delusions, including one of the most common, a persecutory theme. The origins of this and other themes remain unclear, but may be important theoretically and therapeutically.

The concept of psychosocial stress was defined and the two most researched psychosocial stressors were discussed, namely events and EE. The dominant methodology for assessing stressful life events is the LEDS2 and the dominant methodology for measuring EE is the CFI. Stressful events do commonly occur before the first episode but findings require replication and some questions remain unanswered. About half of informal carers of people with psychosis are rated High EE, including new carers. However, it is unclear why carers differ in their EE status (High versus Low) and on each component (CC, H, EOI). Carers' appraisal may hold the key, but there has been little study of it at the onset of the illness.

Research into psychosocial stress has contributed to psychosocial treatments with demonstrable efficacy. There is now interest in applying such interventions at the first episode

of psychosis, but there is insufficient data on the role of psychosocial stress at the first episode to guide theory or therapy.

This thesis therefore attempts to extend what is known about psychosocial stress at the first episode in three main ways. The first aim is to examine whether events might play a role in the first episode, by testing for a clustering effect before onset. Design features employed will address methodological limitations of previous studies and answer new questions about any event-psychosis relationship. The second aim is to test if a link can be found between event type and delusional theme. The third aim is to test the validity of a carer appraisal model of EE, including when patient illness-related factors are controlled. All three studies have theoretic and therapeutic implications for psychosis.

Chapter 2:

Stressful Life Events Before the First Episode of Psychosis

2.1 INTRODUCTION

The relationship between the first episode of psychosis and prior stressful life events ('events') is of vital importance both to theoretical models of psychosis aetiology and to early intervention to reduce positive symptomatology and relapse rates. This chapter will examine the nature and strength of the relationship between prior events and first episode psychosis. It will first discuss the specific reasons why events before first episode psychosis are important. Secondly, it will identify key conceptual and methodological issues and thirdly, the studies of events before first episode psychosis will be reviewed. Discussed in the final section are gaps in the literature and how the present study will attempt to address some unanswered but interesting questions.

2.2 WHY STUDY EVENTS BEFORE FIRST EPISODE PSYCHOSIS?

2.2.1 Clinical Reasons

Clinically, if events are aetiologically involved in the first episode of psychosis this has major implications for early intervention. The reduction of positive symptomatology and relapse rates might be achieved by preventing the deleterious effects of events at biological, psychological and social levels. If events do play a role in onset, then using biological, social and psychological interventions before onset in high-risk groups might even prevent a proportion of new cases of psychosis (e.g. McGorry, 1998).

A further reason for studying events is that they may influence outcome in a variety of ways. The presence of events just before onset may indicate a less severe illness in general (Castine et al., 1998), or a less severe relapse episode (Van Os et al., 1994), implying that people without prior events might need clinical priority. On the other hand, childhood events such as sexual abuse (Greenfield, Strakowski, Tohen, Batson & Kolnbrener, 1994) or other traumatic experiences and adverse social circumstances (Doering et al., 1998) may predict a more chronic course.

Trauma histories may be more common in first-episode patients whose symptoms are unresponsive to medication, compared with those whose symptoms are responsive (Garety et al., 2001). In one study patients who experienced events *after* onset took three times longer to achieve recovery than those who did not (Johnson & Miller, 1997).

Even if events were to have no implications for the onset or course of psychosis, they are worthy of study in their own right. This is because events are very common in people with psychosis (Mueser et al., 1998) and may influence non-psychotic psychopathology such as depression (e.g. Birchwood et al., 1993) and post-traumatic stress disorder (e.g. Mueser et al., 1998; Morrison, Bowe, Larkin & Nothard, 1999; Hamner et al., 2000).

For all these reasons, events appear to be an important clinical variable in psychosis. Fowler (2000) discusses the crucial importance of assisting people with early psychosis to develop a wider understanding of how their personal history and symptomatology interact. This is likely to help with early adjustment to psychosis (Jackson & Iqbal, 2000).

2.2.2 Theoretical and Methodological Reasons

Most of the data on which stress-vulnerability frameworks of psychosis are based come from non-first episode studies, and this has led to the development of comprehensive models of relapse (e.g. Nuechterlein et al., 1994). If events precede the first episode, then this is stronger evidence that they play a role not just in relapse, but in aetiology as well.

Yung (1998) reviews many of the methodological advantages of first episode psychosis designs. After first onset an extensive array of variables is likely to contaminate any relationship between events and psychosis. These include both neuroleptic medication (Leff, Kuipers, Berkowitz, Vaughn & Sturgeon, 1983) and co-morbid substance abuse as a coping strategy for psychotic symptoms (Roth & Fonagy, 1996). Psychotic episodes themselves may also provoke further events, both general (e.g. loss of relationships) and iatrogenic (e.g. compulsory admissions) (Rooke & Birchwood, 1998; Birchwood et al., 1993). The sensitisation hypothesis (see Post, 1990) implies that if events do influence the expression of psychosis they may do so preferentially before the first onset. There is increasing evidence that this may be the case for major depression (e.g. Lewinsohn et al., 1999; Kendler, Thornton & Gardner, 2000).

Interestingly, Brilman and Ormel (2001) recently found that the first episode of depression was associated with more severe events than later episodes. Consistent with a sensitisation hypothesis, a recent psychosis study found that patients with three or less episodes of schizophrenia had significantly more stressful life events in the three months before admission than those with more than three episodes (Castine et al., 1998).

So, overall, the study of first episodes permits research on questions that are unique to onset, and at the same time avoids many variables which might confound an aetiological interpretation. However, studying the first episode does not automatically overcome all methodological problems, as discussed in the ‘Conceptual and Methodological’ section later in this Chapter.

2.3 THE PREVALENCE AND PATTERN OF EVENTS BEFORE FIRST EPISODE PSYCHOSIS

Four issues pertaining to the link between events and subsequent first episode psychosis are important to highlight. First, if events precede psychosis which are *independent* (i.e. clearly not caused by the illness), this strengthens the hypothesis that events are causal to the onset of psychosis rather than caused by it. However, it is not essential to the hypothesis because, as many have pointed out (e.g. Rabkin, 1993; Day, 1989), it would still allow for the possibility that non-independent events might determine whether any pre-morbid vulnerability, at risk state or prodromal period lead to florid first episode psychosis. If events are independent then this allows clearer interpretation of associations found between events and onset. Secondly, if events, especially independent events, occur at an increasing rate in the period before psychosis - a ‘*clustering*’ effect - then this strengthens the inference that they are aetiologically implicated in the psychosis. Thirdly, if events, especially independent events, *occur more commonly than in the normal population*, then this also facilitates an aetiological interpretation of the role of events. A final issue is that if particular *types* of events appeared to precede psychosis then they might be exerting a causal influence.

2.4 CONCEPTUAL AND METHODOLOGICAL ISSUES RELEVANT TO LINKING EVENTS WITH FIRST EPISODE PSYCHOSIS

Before discussing the evidence from studies of events preceding first episodes of psychosis, it is necessary to highlight some further conceptual and methodological issues. In doing so, the rationale for key design features of the present study will be outlined. The issues in the area are numerous and covered in several reviews (see in particular, Brown & Harris, 1989; Norman & Malla, 1993b).

2.4.1 Factors That Might Camouflage an Event Link at First Episode

Within a stress-vulnerability framework (e.g. Nuechterlein et al., 1994), psychosis emerges as a result of a multiplicity of interacting factors. Broadly categorised, these are vulnerability, protective and moderating factors. It is important to control for such factors so that any association between events and psychosis is not camouflaged. However, an association found between events and psychosis even when such ‘camouflaging’ factors are not controlled, suggests that any link is fairly robust.

2.4.2 Nature of the Relationship between Events and First Episodes of Psychosis

It is still not currently known whether events are formative or triggering of psychosis (e.g. Brown, Harris & Peto, 1973). However, within a stress-vulnerability framework, the relative importance of events is thought to vary according to biological vulnerability. It is also possible that events are merely triggering of psychosis per se, but formative of specific illness parameters, such as course or affective disturbance.

2.4.3 Direction(s) of Relationship between Events and First Episode Psychosis

The general relationship between psychosocial stress and psychosis is complex because of “mindboggling” (Spring, 1989, p.339) methodological difficulties.

At least four possible relationships exist between psychosocial stress and psychosis. First, psychosocial stress may lead to psychosis, as will be discussed below. Secondly, psychosis itself can be seen as a stressor which comprises stressful events (e.g. relapses) and difficulties (e.g. residual symptoms) (Birchwood, Mason, MacMillan & Healy, 1993). Thirdly, psychosis can lead to environmental stressors such as life events (e.g. Mueser, et al., 1998). Fourthly,

psychosis and psychosocial stress may have a reciprocal, iterative relationship (Harrop, Trower & Mitchell, 1996).

Many studies have sought to isolate the causal role of events by accurately dating onset and only asking about events which precede onset. However, separating the direction(s) of effect is difficult even at the first episode because the signs of psychosis may appear before the onset of formal symptoms (as discussed in Chapter 1). Despite this, the issue can be dealt with by rating all events on a seven-point 'Independence' scale. This is the degree to which a person causes the event as opposed to it being fateful and uncontrollable (Brown & Harris et al., 1992, LEDS2 Manual, p.65-66). In this way, differing degrees of certainty about direction of effect can be tested. The dating of onset from positive symptoms means that studies have typically not recruited patients with more insidious onsets, and so the results might not generalise to this group.

2.4.4 Instrumentation Issues

Most instrumentation issues have been reviewed in Brown and Harris (1989; 1978). Selected here are the issues most relevant to the present study. Measurement error is more likely to be reduced by obtaining event information from participants, rather than from secondary sources such as the case notes or staff feedback. To tackle the potential risk of participants forgetting or recalling inaccurately, a semi-structured interview with extensive recall prompts, cross-referencing of answers and a sceptical and conservative approach can be used (e.g. Brown & Harris, 1989). A semi-structured interview rather than a predefined checklist (e.g. Jacobs & Myers, 1976) also allows the interviewer to check that respondents understand the question before stating they have experienced an event. Ratings by a researcher are likely to be more valid than ratings by the subject when examining the effect of external stressors on psychosis. This approach minimises memory problems due to distortions of the illness and 'effort after meaning'. Situational features are likely to affect the stressfulness of events, so it is more valid to rate the event 'contextually' (Brown & Birley, 1968; Brown & Harris, 1978) than to use pre-defined weightings to events.

There are many stress-related concepts that could be used to capture the severity of events. Day (1989) notes that several have been tried such as 'undesirability', 'upset', 'hazardness', 'social readjustment' and 'threat'. The concept of 'threat' (Brown & Birley, 1968; Brown &

Harris, 1978; Brown & Harris, 1989) refers to the sum total of unpleasantness associated with the event. It comprehensively combines the person (e.g. history), the event (e.g. likely duration) and the situational features (e.g. social support) that can affect the stressfulness of the event. The concept has proved useful in many fields of research, including depression, anxiety and physical disorders (see Brown & Harris, 1989). It has also been used successfully in several event studies of psychosis (e.g. Bebbington et al., 1993) including first episode studies (e.g. Day et al., 1987). As noted in Chapter 1, Brown and Harris have also developed a range of measures which are components of threat, such as loss, danger and humiliation. These appear to be reliable and predictively valid in depressive and anxiety samples (e.g. Finlay-Jones & Brown, 1981; Brown, Harris & Hepworth, 1995). However, these dimensions have not been used in studies of psychosis. Rating events on specific dimensions of stress is an important methodological advance. This technology is suitable to investigate the event – delusional theme hypothesis described in Chapter 3.

The instrument that combines the major features relevant to testing an aetiological role for events is the Life Events and Difficulties Schedule, Version Two (LEDS2) by Brown and Harris et al. (1989). It involves a semi-structured interview (not a simple checklist), the researcher (rather than the participant) rates the stressfulness, the rating is contextual, and event independence is rated. The underlying stress concept (threat) has proved useful in the context of first episode psychosis. It is seen by many as the gold standard research instrument in the area (Creed, 1993). The reliability and validity information of the LEDS2 is described in Chapter 5 (The Method).

2.5 INDIRECT EVIDENCE THAT EVENTS MIGHT INFLUENCE THE FIRST EPISODE OF PSYCHOSIS

Indirect evidence that events might play a role in the first episode of psychosis comes from a wide range of sources. These are discussed briefly before the more direct evidence of event studies before first episode psychosis is considered.

Benzodiazepine administration can improve psychotic symptoms (Wolkowitz & Pickar, 1991; Kirkpatrick et al. 1989) while withdrawal can precipitate psychosis (Roberts & Vass, 1986). Over-intensive psychosocial treatment seems to encourage the re-emergence of psychotic

symptoms (e.g. Drake & Sederer, 1986). The ability of High EE to predict psychotic relapse (e.g. Butzlaff & Hooley, 1998) supports an aetiological role for events in psychosis. Independent events appear implicated in psychotic relapse (e.g. Brown & Birley, 1968; Bebbington et al., 1993), and so might also influence onset. The interactions observed between the carers' level of EE and events at later and first relapse are consistent with both acting as stressors on psychosis (Leff & Vaughn, 1980; Leff et al., 1990). The interaction of stressful events with medication is also consistent with this (Leff et al., 1983).

The results of individual and family interventions are also supportive of stress playing a role in psychotic relapse. A recent review of the concept of reactive psychosis concluded that such cases do exist and that the concept is a valid one (Ungvari & Mullen, 2000). With reference to indirect evidence from first-episode studies, one study found that social support predicted relapse in psychosis patients over a 5 year period (Castine et al., 1998). As noted earlier, there has been a preliminary finding that inpatients who have first episode psychotic symptoms that are unresponsive to medication report severe trauma histories and are more commonly compared with those whose symptoms are responsive (Garety et al., 2001). There is, therefore, a great deal of background evidence that psychosocial stress may play a role in onset.

2.6 DIRECT EVIDENCE THAT EVENTS MIGHT INFLUENCE THE FIRST EPISODE OF PSYCHOSIS

This section reviews studies of events before the first episode of psychosis. Studies that fail key methodological requirements, for instance, by assessing events in the period up to admission rather than before onset, will not be discussed.

2.6.1 Types of Research Designs Used

The studies vary on three key design features. Some studies investigated event rates before psychosis, while others looked at onset rates after a particular type of event. Some studies used a case control design, comparing psychosis patients with controls, while others used a within-sample design and looked for clustering of events before onset. Studies also varied on whether they used a group or case-study approach.

A review by Norman and Malla (1993a, 1993b) of events and schizophrenia included a comparison of studies which involved first episode/admissions only with those which contained mixed first and subsequent episode samples. They concluded there was no consistent evidence that onset and relapse differed in their relationship to prior independent events. However, they did acknowledge that first episode participants in the mixed samples might have diluted differences between the two groups of studies. Also, given the uneven methodological rigour and approach between studies, they acknowledge that this conclusion was merely tentative.

2.6.2 Studies Which Found Non-Significant Results

Surprisingly, there are no published studies which have used a case-control design with a group of exclusively first *episode* psychosis patients. Two methodologically stronger studies did use a case control approach and tested for an association between independent events and first episode/admission psychosis but obtained non-significant results. Jacobs and Myers (1976) recruited a group of first-admission schizophrenia patients and compared the event rate with a group of randomly selected normal controls. Although the patients had more events than controls, the excess was not significant for independent events. However, the study used a checklist and did not rate stress contextually. Although the study was one of only two that examined the full year before onset, the possibility of a clustering effect before onset was not examined.

Al-Khani, Bebbington, Watson & House (1986) also used a retrospective case control design, with a group of mixed first and non-first episode patients in Saudi Arabia. They rated the threat of the events contextually with a semi-structured interview, although they did not use the LEDS. Analysis of the first episode sub-sample (n=21) indicated that there was no significant difference between the controls and the psychosis group. However, there was an almost significant trend for events to be more frequent in the final three-week period before onset, as compared to earlier periods. The controls did not display this pattern. For first admission women only, there was an excess of events compared to controls. The numbers of first episodes was fairly small and the authors suggest this as a reason for the main non-significant result. So both studies that failed to find an aetiological role for events at first episode have methodological limitations that can potentially explain their non-significant results.

2.6.3 Studies Which Found Significant Results

Several different types of event studies have found evidence supporting an aetiological role for events before the first episode of psychosis. The single such study with a case control design was Brown and Birley (1968), involving 50 patients with schizophrenia and 325 randomly selected normal controls. Approximately half the sample were first admission, mainly first episode. The original LEDS instrument was used in a semi-structured interview covering the three months before onset, with contextual rating of events on threat. There was an excess of independent events compared to controls, and this was most pronounced just before onset. It was reported that there was no difference between first admission and relapsing patients with respect to life event results.

The only study that has used a group of exclusively first *episode* patients was the WHO study (Day et al., 1987). Although it was not a case controlled study, patients were recruited consecutively, involving a large number (386) across nine different countries. The assessment involved a LEDS type approach modified for cross-cultural research and covered the three months before onset. The results substantially replicated the clustering pattern of events in the three weeks before onset that Brown and Birley (1968) found. One recent (apparently first episode) study used a different type of design, using patients with and without a family history of psychosis and compared their rate of life events before onset (Das, Malhotra, Basu & Malhotra, 2001). Consistent with a role for events, it was found that patients with a negative family history of psychosis had significantly more events. However, this study used a checklist, did not rate stress contextually and also did not report rating the independence of the events. Further, only 14% of the events included in the analysis were rated as definitely 'undesirable'; the rest were 'desirable', or 'ambiguous'. This means that the results primarily relate to life events per se, rather than stressful life events.

Several studies approached the issue by identifying samples that are defined in relation to a single type of event. Four military studies have found an excess of first episode psychosis in the period soon after recruitment as opposed to later in training (Steinberg & Durrell, 1968; Wallis, 1965; Beighley, Brown, & Thompson 1992; Knobler et al., 2000), supporting a role for psychosocial stress. Some studies have found an excess of sexual abuse before psychosis (Greenfield et al., 1994; Gift, Wynne & Harder, 1988), or an excess of psychosis after sexual

abuse (Ensinck, 1992). However these studies have methodological weaknesses such as a very high refusal rate (Greenfield et al., 1994) or absence of clear onset and event dating (Gift et al., 1988), so any excess could be an artefact. Marriage has also been documented as precipitating an excess of first-episode psychosis in both a group (Fisch, 1992) and case (Shankar, 1991) study. However, representativeness of the results is again an issue. Slade and Bentall (1988, p.88) note that several early case studies reported traumatic events leading to psychotic symptoms, such as being involved in a mining accident, a sustained military operation (without sleep) or being a hostage. There are also numerous other more recent first-episode case studies in the literature, discussed further in Chapter 3, that indicate independent events can precede the onset of psychosis proper. However, many people in the normal population experience events and do not become psychotic, so some cases may occur by chance alone.

There has been debate over whether or not people with psychosis are particularly vulnerable to certain kinds of stressors - the 'specificity' hypothesis. Although many workers have searched for specific event types in their data sets (e.g. Brown & Birley, 1968; Jacobs & Myers, 1976) they have generally not found any. This may be because event categorisations have been at the topographical level rather than at a more meaningful psychological level. The one psychological characteristic that has received support has been "intrusiveness" (Harris, 1987), which refers to the unwanted breach of personal boundaries by people outside the person's primary group or by an organisation. Harris (1987) re-analysed the Brown and Birley (1968) study, and found that intrusive events were twenty times more likely in people with schizophrenia than controls (20% v 1%) three weeks before onset. Harris does not report separate figures for people in their first episode, but the findings are suggestive since other analyses did not reveal any difference in event relationships between first admission and relapse patients. The theory is supported by studies mentioned earlier on sexual abuse before first episode and studies of the effects of military training, which is inherently highly intrusive. Day et al. (1987) analysed the WHO data, and also found a high rate of intrusive events in the one week before onset in the four western centres (23%, 10%, 18%, 23%). This is much higher (10-23 times) than the normal controls in the Brown and Birley (1968) study. An additional source of evidence, albeit indirect, comes from the EE literature, as people rated high on EE are also often intrusive towards the person with psychosis.

2.7 EVALUATION OF THE ROLE OF STRESSFUL EVENTS BEFORE FIRST EPISODE PSYCHOSIS

In synthesising the evidence about events before first episodes of psychosis, the absence of a definitive study means that a judgement needs to be constructed out of pieces of evidence accumulated from different types of studies.

From the studies reviewed, it can be concluded that stressful events do commonly precede first episodes of psychosis and that this is also true of independent events (Brown & Birley, 1968; Jacobs & Myers, 1976; Al-Khani et al., 1986; Day et al., 1987). By far the largest data set was that of Day et al. (1987) who had 386 first episode participants. Day et al. estimated that the lower limit for an independent event occurring in the three months before psychosis was less than 50% and the upper limit was 65%. Although Day et al. do not present the calculation based on *all* events, the prevalence of events including non-independent events before onset would probably be much higher. So the potential is there for a large effect size. The only attempt to estimate the actual effect size of stressful life events at first episode psychosis was by Paykel (1978), who used relative risk. When he re-analysed Jacobs and Myers (1976), combining it with data from another study (Jacobs et al., 1974) he found a relative risk of 3.0-4.5 in the 6 months before onset. This is a difference of theoretical and clinical importance.

Compared to Brown and Birley's (1968) normal control group, it can be seen that independent events seem to occur with greater frequency before first episodes of psychosis than in the general population (Brown & Birley, 1968; Day et al., 1987). It can also be concluded that events cluster before onset (Brown & Birley, 1968; Day et al., 1987; Al-Khani et al., 1986). The issue of event specificity has some support from a diverse range of studies, in the form of the intrusiveness concept. However, other higher order psychological dimensions would also need to be tested before concluding that intrusiveness is associated more than other forms of stress before first onset.

There is, therefore, suggestive although not definitive evidence that events are aetiologically implicated in the first psychosis episode, that they might exert a large effect and that the influence may occur in about half of first episodes.

2.8 LITERATURE GAPS AND NEXT STEPS

2.8.1 Literature Gaps

Several design aspects are lacking in studies of stressful events before first episode psychosis. This means that replication is required on some issues and interesting questions are left unanswered relating to event timing, independence, severity and type.

The one study which tested stressful looked a full year before onset (Myers & Jacobs, 1976) used a checklist, which means their results require replication in order to assess the validity of their findings. No first episode study has so far tested if the clustering effect will be found not only in the final three weeks versus preceding nine weeks, but also when comparing the final three months with the preceding nine months. This relates to possible stress-incubation before onset (see Bebbington et al., 1993b). Independence is also an issue which is unexplored in terms of a clustering effect by comparing the final three months before onset with the preceding nine months. Garety et al. (2001) place key importance on the external attribution for symptoms in psychosis, and independent events might encourage just such a decision. It is therefore unknown if independence might exert an effect that is more distal in time.

The issue of event severity is important because of the sensitisation hypothesis, which predicts that the onset will require a greater severity of stress than subsequent relapses. The main study which included an investigation of event severity is Bebbington et al. (1993). They found that independent events rated 1 (marked threat) or 2 (moderate threat) were significantly in excess compared to a control group. They also found that 'possibly independent' events rated 3 (some threat) in the LEDS scheme were in excess compared to controls in the final three months, although this was reduced to a trend ($p=0.08$) when only independent events were considered. However, 36% of the sample were first episode cases, which might have had the net effect of reducing the p-value for the overall sample with respect to events of more minor severity. The possibility has never been tested that, consistent with the sensitisation hypothesis, only events of higher severity may cluster before the first episode.

The only study to report on what types of events occur before the first episode is Day et al. (1987). However, Day et al. used only lower-order categories (such as 'housing' or 'finance')

and only asked about the final three months. No study has so far descriptively investigated the types of events before first episode psychosis using the higher-order LEDS2 classifications (i.e. loss, danger, humiliating, intrusive, self-esteem,), and none have reported events a full year before onset.

2.8.2 Next Steps

The main aim of the present study will therefore be to test for a clustering effect in the final three months as well as attempt to replicate earlier work that found a clustering effect in the final three weeks before onset. The study will employ a within-group design, include a broad range of functional psychosis, include only first-episode patients, and for the first time the LEDS instrument will be used before the first episode of psychosis. Issues relating to event timing, independence, severity and type will also be investigated.

2.9 CHAPTER 2 SUMMARY

This chapter has discussed stressful events before the first episode of psychosis. Events before first episodes of psychosis are clinically important because they would support the early use of biological, psychological and social interventions to improve early outcome, and perhaps even to prevent some new cases. Events before the first episode of psychosis are also important for theoretical models of aetiology. Methodologically, the first episode represents the only opportunity to study aetiology in the absence of potentially confounding variables. Indicators that events might play a role in the first onset include events being independent, clustering before onset and being in excess compared to normal controls. Key conceptual and methodological issues relevant to the present event study were identified.

There is a wide and diverse range of indirect evidence that events might influence the first episode of psychosis. Direct evidence comes from studies that assessed events before first onset. The initial onset of psychosis is associated with prior events, and this is also true of independent events. The effect size of events on first episode psychosis is difficult to estimate, but there are indications that it may be both theoretically and clinically significant. Events seem to cluster before onset, and are sometimes, but not always, in excess of normal population rates. There is some evidence of intrusive event specificity for psychosis but other stress dimensions need testing.

The present study aims to test for a more distal clustering effect of events before the first episode. The study includes various design features which both address the methodological limitations of previous studies and also answer some new questions. These questions include stress-incubation, sensitisation, event independence and what types of events befall patients in the year before onset.

Chapter 3:

Psychosocial Stress and the Themes found in Delusions

3.1 INTRODUCTION

The origins of the contents of delusions remain almost as mysterious today as in previous times. Are the contents really “un-understandable” (Jaspers, 1963), merely “empty speech acts, whose inferential content refers to neither world or self” (Berrios, 1991)? Or are there underlying patterns and regularities waiting to be discovered in the content of this key symptom of psychosis? Our understanding of why people experience different types of delusions is only just beginning. Yet the content might be clues to the nature of individual stress-vulnerability (Hingley, 1992). The content may also imply which factors to target in psychological interventions aimed at lowering positive symptomatology and improving quality of life. This chapter will discuss evidence suggesting that psychosocial stress may influence the contents of delusions and, in particular, that intrusive events might influence the development of a persecutory theme. In order to discuss this possibility, delusions will be defined, their main characteristics highlighted and theories about their origins discussed. After this, theories of causation of themes will be reviewed, with particular emphasis on the possible role of psychosocial stress.

3.2 DELUSIONS: DEFINITION AND CHARACTERISTICS

The definition of a delusion has challenged workers for centuries and remains unsatisfactory today. A full discussion of the definition of delusion is beyond the scope of this thesis and the reader is referred to Garety and Hemsley (1994) for an in-depth review. The operationalised definition used for the purposes of this thesis will be that of the Schedules for Clinical Assessment in Neuropsychiatry (SCAN, WHO 1992; see Appendix 21). The SCAN definition does have limitations. For example, it stipulates that conviction must be ‘compelling’ and that the delusion is not susceptible to modification by experience. Yet both of these criteria are contrary to empirical data (Brett-Jones, Garety & Hemsley, 1987; Kuipers et al., 1997). However, the SCAN definition appears to have sufficient sensitivity and specificity for the purpose of the studies carried out for this thesis.

Garety and Hemsley (1994) note there has been a gradual shift away from viewing delusions as discrete entities, discontinuous with normal beliefs. The modern approach is to conceptualise them as multi-dimensional phenomena that may be placed at various points along any given belief dimension, continuous with normality. Their data show that delusions are not always placed at the extreme point of a dimension, so that the common defining characteristics of a delusion are neither necessary nor sufficient. Garety and Hemsley (1994) state that the most characteristic feature of delusions is their high level of conviction, although this can fluctuate over time, as can other dimensions. Many people will express high levels of preoccupation, interference, undismissability, unhappiness and pervasiveness, although others may not. Oulis, Mamounas, Hatzimanolis & Christodoulou (2000) provide a factor analysis that involves an interesting different list of delusional characteristics. Generally, Garety and Hemsley (1994) report that the dimensions are relatively independent of each other, a finding also supported by Oulis, Mavreas, Mamounas & Stefanis, (1996). Delusions contain a very wide range of contents, an issue explored further later in this chapter.

3.3 THEORIES OF THE CAUSES OF DELUSIONS

This section will outline factors that have been causally implicated in the formation of delusions. Delusions have, principally, been linked to perceptual abnormalities, meta-representation deficits and beliefs about the self, encompassing both ‘malfunction’ and ‘motivational’ theories (Winters & Neale, 1983). This thesis approaches the study of delusions at the psychological level and at a social-cognitive interface. Therefore a discussion of possible organic and genetic mechanisms will not be attempted.

3.3.1 The Causation of Delusion

The understanding of delusional formation has benefited considerably in recent years from much new empirical data. However, Garety and Freeman (1999) note a number of general weaknesses of this literature. These include treating delusions as binary rather than as continuous variables, not assessing for more than one dimension of the delusion, an over-reliance on cross-sectional studies, and the non-reporting of study refusal rates. The main models proposed of delusional formation have been those of Maher (1974; 1988), Frith (1979; 1987; 1992), Bentall (e.g. Bentall et. al., 1994; Bentall & Kinderman, 1998) and Garety and Hemsley (1994). Models vary in their ability to account for the formation (as opposed to the

maintenance) of delusions. None of the data upon which the models were built came from a first episode psychosis study. Yet this is a time when clues to formation, as opposed to mere maintenance, might be more apparent and more testable. Models also vary in their ability to account for the heterogeneity of delusional content.

(i) Perceptual Abnormality

Maher (1974; 1988) proposed that delusions are secondary to a perceptual abnormality that prompts an individual to search for an explanation, derived using intact cognitive processes. A perceptual abnormality may account for some delusions, particularly perhaps those that occur in the context of a neurological deficit (Ellis, 1998). However, a perceptual abnormality is not a sufficient condition for a delusion and may not even be necessary (Chapman & Chapman, 1988). Also, many studies indicate that the reasoning processes in some delusional individuals are not intact (Garety & Freeman, 1999).

(ii) Meta-Representation

Frith (1979) proposed that patients with schizophrenia may have a defect in a hypothesised mechanism that limits the information available to consciousness. In this theory, delusions result from unexpected information entering consciousness, which demands an explanation. Building on this, Frith (1987; 1992) proposed that what underlies many of the positive symptoms of schizophrenia is an impairment in the ability to represent one's own mental states and the mental states of others. Frith and colleagues elaborate on how such 'theory of mind' (TOM) deficits could play a role in delusion formation (e.g. Frith & Corcoran, 1996; Corcoran, Cahill & Frith, 1997). The model hypothesises that the type of delusion that forms depends on the precise nature of the representational skill impairment. Garety and Freeman (1999) point out that the theory of mind deficit results might be confounded by symptom severity, and that some attempted replications have been unsuccessful. In addition, TOM deficits appear to be state rather than trait influences, because when not deluded, patients perform as well as non-patients (Drury et al., 1998).

(iii) Motivational Accounts

A *motivational* causation for some types of delusions has been proposed by Winters and Neale (1983), and developed by Bentall et al. (1994), who constructed a model of delusion formation to account for just one type, persecutory delusions (although Bentall & Kinderman, 1999 review work on a motivational account of grandiosity too). They argued that paranoia is driven by low self-esteem/self-discrepancies. The central mechanism for preventing low self-esteem information from reaching consciousness is an excessively external attributional style for negative events. This is coupled with an excessive tendency for people to regard positive events as being caused by themselves. The external attribution style appears personal (rather than situational or chance) in nature (Kinderman & Bentall, 1997). Maintenance of the persecutory theme is hypothesised to be facilitated by an information processing bias that preferentially attends to threatening stimuli in the environment (Kaney & Bentall, 1989) and from memory (Kaney, Bowen-Jones & Bentall, 1997). Kinderman and Bentall (2000) have found evidence for a possible iterative relationship between self-representation and an external attributional style, and discuss how persecutory delusions may be an end sequence development of this. However, a recent review of cognitive approaches to delusions concludes there is no strong evidence for a key part of the model, namely, that persecutory delusions serve as a defence against low self-esteem (Garety & Freeman, 1999).

(iv) Reasoning

Garety and colleagues (see Garety & Freeman, 1999, for a review) have found experimental evidence for a reasoning bias in individuals with delusions, that appears to contribute to the formation and maintenance of some delusions. A ‘jumping to conclusions’ reasoning style has been supported in many studies. Studies continue to explore the precise nature of the reasoning process abnormality (e.g. Linney, Peters & Ayton, 1998). Garety and Freeman (1999) discuss the work of Dudley, John, Young & Over (1997) who found that a ‘data gathering bias’ may lead to the ‘jumping to conclusions’ reasoning style. In keeping with the likely heterogeneity of causation, Garety and Hemsley (1994) have included a reasoning bias in a multi-factorial model of delusion formation and maintenance, based on what is known about normal beliefs.

Each of the models may plausibly contribute to the probable causal chains involved in delusion formation and maintenance. As noted, it is highly likely that a delusion is the end result of a

complex set of dysfunctions. As Chadwick (1992 p.92) put it, “it is a result of a whole orchestra of processes playing in sinister harmony”.

3.4 THE THEMES IN DELUSIONS: CHARACTERISTICS AND TYPES

The content of delusions refers to all the information contained within them. In contrast, the concept of *theme* allows a sub-group of the contents to be grouped together according to some underlying commonality. From the neurosis literature, Lebowitz and Newman (1996) describe themes as cognitive-affective meaning structures and processes. Each theme represents a particular cognitive-affective meaning or schema that individuals use to organise their relationship to self and the world. Studying psychotic themes is a logical extension to Persons (1986) proposal that researching individual symptoms can sometimes be more revealing than studying broad diagnostic categories. Since Neale (1988) points out that different delusions may be the result of different mechanisms, the concept of theme allows more specific hypotheses about causation to be tested. The theme can be at the level of fine detail, as in the delusion that one is pregnant. Alternatively, themes may be ‘higher order’ i.e. more general, and so broader in their potential theoretical and clinical implications. Spitzer (1992) points out that there is only a narrow range of themes that occur in psychosis around the world. Some of the most common higher order themes are persecutory, referential, grandiose and depressive. The study by Castle et al. (1998), of first episode psychosis showed that 75% of their sample experienced a persecutory delusional theme, and 82% experienced a grandiose delusional theme. Delusional themes may re-emerge in successive psychotic episodes (Jorgensen & Jensen, 1994). However, empirical evidence on the *determinants* of these themes is only just emerging. Evidence related to the causation of themes will be discussed shortly, but first, it is important to clarify why the themes found in delusions are worthy of research.

3.4.1 Why are the Themes in Delusions Important?

Delusional themes are important clinically because they have a range of links with other psychopathological phenomena. Grandiose delusions predicted longer episodes and shorter remissions in a first episode study (Eaton, Thara, Federman & Tien, 1998), and were one of three key factors that predicted admission in another study (Castle et al., 1998). Grandiose themes also interfere with motivation to engage with cognitive behaviour therapy, as there may be no distress (Fowler et al., 1995). Depressive delusions predicted better outcome in another

first admission study (Geddes, Mercer, Frith, MacMillan, Owens, & Johnstone, 1994). With reference to persecutory delusions, they are a source of considerable distress for those who experience them (Fowler et al., 1995; Freeman & Garety, 1999). Patients who hold persecutory delusions are also more likely to be violent than patients who do not hold such delusions (Cheung, Schweitzer, Crowley & Tuckwell, 1997). At a theoretical level, the themes found in delusions and voices could imply something about the nature of individuals' vulnerability to psychosis (Hingley 1992). Understanding the causes of themes would also have implications for stress-vulnerability frameworks of psychosis, which are currently silent on the issue.

3.5 ADDITIONAL METHODOLOGICAL ISSUES RELEVANT TO DELUSIONAL THEME RESEARCH

Although the study of individual symptoms has many advantages, Persons (1986) also noted that this approach tends to ignore the complexity of the clinical presentation. Delusional themes usually appear in clusters, which means that if an association is found between a variable and a delusional theme, it might actually be due to the co-existence of a co-morbid theme. For example, the key paper which supports a role for self-esteem in persecutory delusions involves at least several patients who clearly also have a grandiose delusional theme (Lyon, Kaney, & Bentall, 1994, Appendix 1, p.644). Given that self-esteem is hypothesised to lead to grandiose delusions (e.g. Winters & Neale, 1983), the possibility cannot be ruled out that the significant results obtained in the paper by Lyon et al., were due to this or indeed some other theme present, rather than to a persecutory theme. This means it is important to consider whether there is any rationale for a theme which is not the dependent variable being associated with the independent variable. Fear, Sharp and Healy (1996) are one of the very few to allude to the problem of co-morbid themes. Their study on attributional style in delusions included a sample with a variety of themes. They state that further testing is required to determine if their work applies to all patients with delusions or just a sub-group with a particular theme. Davis and Stewart (2001) also mention the issue of co-morbid themes, when they suggest that the social information processing biases in people with persecutory delusions might differ according to whether or not the person also holds grandiose delusions (p.258).

A similar methodological problem pertains to independent variables, which - like themes - also do not occur in isolation from one another. Studies that specify and measure only one independent variable risk another factor confounding any association discovered. For example, it has been argued that some of the earlier work on linking self-esteem to a persecutory theme (reviewed by Bentall, 1994) might be better accounted for by attributional style (Fear et al., 1996), which is now thought to be linked with self-esteem (Kinderman & Bentall, 2000).

The above two methodological problems entail that where it is thought that co-morbid themes might confound the theme of study, or where the independent variable might be confounded by correlates, it is helpful to control statistically for these possibilities. Another methodological issue concerning theme research is the theoretical possibility that some influences might only affect a sub-group within a theme (Trower & Chadwick, 1995; Freeman & Garety 2000). Finally, Birchwood (1999b) warns against the cognitive modelling of delusions in isolation from the social context in which they occur.

3.6 POSSIBLE FACTORS AFFECTING DELUSIONAL THEME FORMATION

OTHER THAN PSYCHOSOCIAL STRESS

Until recently the dominant view was not conducive to investigating themes in psychosis, as the earlier quotes from Jaspers (1963) and Berrios (1991) show. However, Bentall et al. (1994) point out that if Berrios was correct about delusions being meaningless, they would contain a wide range of unconnected themes. Yet in fact the contents of delusions often reflect concerns about the individual's position in the social universe.

As Garety and Hemsley (1994) discuss, there may not only be different mechanisms involved in the formation of different themes, but there may also be different routes to the same theme. There might even be more than one type of theme within traditionally accepted theme categories (Trower & Chadwick, 1995; Freeman & Garety, 2000). Themes that arise in the context of organic damage may develop by different mechanisms to the themes found in functional psychosis (Cutting, 1997). Therefore only evidence relating to functional psychosis rather than other disorders such as dementia, head-injury etc. will be discussed. Only a few factors have so far been implicated in theme formation. The main ones have related to meta-

representation, beliefs about the self and attributional style, mood, historical period, culture and psychosocial stress.

The main focus of the present study is the possible role of psychosocial stress in delusional theme development, and in particular, a persecutory theme. However, before focusing on this, in order to place the central hypothesis in context, it is worth briefly summarising studies which have found evidence that factors other than psychosocial stress may influence themes other than a persecutory theme. It is also worth outlining the most recent cognitive model of persecutory delusions, as this helps to place the psychosocial hypothesis of this chapter in the context of other possible influences on a persecutory theme.

There is some evidence that meta-representation deficits may be involved in delusions of control and reference, but as noted earlier the evidence is weakened by a possible symptom severity confound, and non-replications (Garety & Freeman, 1999). Regarding beliefs about the self, one study found that delusion themes such as referential, grandiose and control appeared to reflect aspects of patients' self-esteem (Bowins & Shugar, 1998). The authors conclude that a central factor driving delusional maintenance is the fact that the types of delusions people have reflect core beliefs they have about themselves. The hypothesis that unstable self-esteem influences the development of grandiose delusions has some evidence (Neale, 1988; Winters & Neale, 1983; Bentall & Thompson 1990; Lyon, Startup & Bentall, 1999; Bentall & Kinderman, 1999). However, the evidence derives from studies on people without psychosis and important aspects of the theory have never been tested (e.g. that the unstable self-esteem is coupled with a special need to succeed in a certain life area). This makes the theory only weakly and partly supported. Many studies have found that a variety of themes can be related to the historical period in which they appear (e.g. Mitchell & Vierkant, 1988; Klaf & Hamilton 1961). Other studies have compared people from different cultural groups with respect to the contents of their delusions and found differences (Westermeyer, 1988, reviews the issue). However, a methodological limitation of historical and cultural studies is that they have typically involved a post hoc qualitative analysis. Stronger evidence would come from a study that used a priori hypotheses about which cultural factors predict with which themes. Overall, it can therefore be seen that there is some evidence that factors other than psychosocial stress might influence various delusional themes.

3.7 POSSIBLE FACTORS AFFECTING PERSECUTORY THEME FORMATION OTHER THAN PSYCHOSOCIAL STRESS

A review of cognitive factors associated with persecutory delusions was recently presented by Blackwood, Howard, Bentall & Murray (2001). It links together many of the factors that have been implicated in delusion formation per se and persecutory theme in particular. In summary, the model incorporates four main psychological influences. An attentional bias means that the patient preferentially attends to threat-related stimuli and preferentially recalls threat-related memories. An attributional bias is involved in terms of an exaggerated self-serving bias, and an external attributional style shapes the content so that negative self-referent events are attributed to malevolence rather than circumstances or chance. A data gathering bias leads the patient into a 'jumping to conclusions' reasoning style. This hasty decision-making combined with a failure to adequately assess incoming new information, particularly for more emotionally salient material, contributes to erroneous inferences, and interacts with the attentional and attributional biases in leading to persecutory delusions. TOM is also included in the model, but is likely to play only a role for a sub-group of people who have more of a disorganisation component to their psychosis. Given the methodological weaknesses of many studies on delusion formation - including delusional theme formation - upon which the model of Blackwood et al. (2001) is based, it should be regarded as tentative. How their cognitive model is compatible with a psychosocial stress influence to persecutory delusions is discussed later in the chapter. Maintenance of persecutory delusions appears to be facilitated by the use of safety behaviours, such as avoidance of the perceived threat (Freeman, Garety & Kuipers, 2001).

3.8 PSYCHOSOCIAL STRESS AND DELUSIONAL THEME FORMATION: METHODOLOGICAL ISSUES

If stressful events carried only one dimension of stress and if psychosis patients had only one type of delusional theme (which varied from patient to patient) then it would be relatively easy to demonstrate relationships between psychosocial stress and delusional themes. However, a common potential difficulty in psychosocial research in general is that events nearly always carry more than one dimension of stress. In the case of delusional theme, this makes it possible that a type of stress that is not designated as the independent variable could be responsible for any association found. For example, starting military training is certainly highly intrusive, but may also involve losses such as leaving home and familiar relationships. One way of dealing

with this is to test also all the other stress dimensions (i.e. loss, danger, humiliation and self-esteem) with the delusional theme. Then if the hypothesised dimension (e.g. intrusiveness) is the only significant link, this would be evidence for 'event specificity'. If another stress dimension was associated with the theme, such as loss, then it could be controlled statistically (e.g. in a logistic regression), to examine if it is associated only by virtue of appearing with the intrusiveness. A similar issue arises with themes because, as noted earlier, they often co-occur. Therefore it is also helpful to conduct post hoc testing of the hypothesised stress dimension with all the other themes in the sample too. If the stress dimension associates only with the dependent variable theme, then this would be evidence for 'theme specificity'. Thus, in order to show that any event-delusional theme link was not confounded by another type of stress or was merely associated with delusions in general rather than a particular theme, both event and theme specificity are important to demonstrate. A further issue is that an ideal stress dimension to test would be one hypothesised to influence only one type of delusional theme; and an ideal delusional theme to test would be one hypothesised to have only one type of psychosocial cause.

Many of the other methodological issues raised in Chapter 2 about linking stress as a causal factor to psychosis are relevant to a discussion of the influence of psychosocial stress on themes. However, two are of particular relevance. First, within a stress-vulnerability framework of psychosis (e.g. Nuechterlein et al., 1994), it is possible that sensitisation may disrupt the specificity of any stress-theme association (see Ramana & Bebbington, 1995). Thus there could be a 'lock and key' fit (e.g. Simpson 1994, p. 298; Parker et al., 1998) between stress and theme that disappears after the first episode because *any* subsequent psychosocial stress might be sufficient to re-trigger the theme. The nature of a psychosocial stress-theme link might, therefore, be obscured unless the study involved only first episode participants. Secondly, an aetiological study of links between psychosocial stress and delusional theme links would be at a particular risk of patients employing 'effort after meaning' to explain their themes. A contextual approach to rating psychosocial stress would therefore be methodologically stronger than relying on patient recall of the severity and quality of particular types of events.

Evidence for a psychosocial stress causation to some themes is divided here into general evidence, more direct evidence in the form of published case studies, and a review of the group studies that have addressed the issue.

3.9 GENERAL EVIDENCE THAT PSYCHOSOCIAL STRESS INFLUENCES DELUSIONAL THEMES

General evidence for a psychosocial stress causation of some themes can be found in the major models of delusion formation, the link between experience per se and themes, the psychiatric recognition of the disorder *Folie a Deux*, and the link between prior ‘concerns’ and the development of themes.

3.9.1 Psychosocial Stress Theme Causation and the Major Models of Delusions

Maier’s view (1974; 1988) that delusions are an attempt to make sense of unusual experiences is compatible with a psychosocial causation. This is because themes might be an attempt to make sense of recent unpleasant, and possibly unusual, stressful events. For example, the intrusive events reported by Harris (1987), such as burglary or police checks, though not as ‘bizarre’ as an internal perceptual abnormality, are not everyday experiences. In line with Frith’s TOM theory, a severely unpleasant intrusive event caused by another person might encourage people to develop biased TOM judgements about the intentions of others.

Garety and Hemsley’s multi-factorial model of delusion formation (1994) allows for events playing a role at several stages. In stage 1, *prior expectations* could be influenced by recent psychosocial stress. At stage 2 *the affectively loaded* current incoming information might be psychosocial stress. At stage 4a the *high arousal* might be induced through events. At stage 6 the *affect reduction* that the formation of a belief allows might have been caused by psychosocial stress. Finally, psychosocial stress might lead to affect which interferes with information processing and contributes to the ‘jumping to conclusions’ reasoning abnormality. Garety and Freeman (1999) note that some studies have found that emotional salience affects people’s reasoning in general and possibly affects the reasoning of people with delusions to a greater extent. This is consistent with a psychosocial causation of some themes.

The model by Garety et al. (2001) of the positive symptoms of psychosis includes a role for psychosocial stress in the onset of delusions. There is hypothesised to be a route directly from an event, and an indirect route through the disruptive effect of emotion on cognitive processes and the formation of maladaptive cognitive appraisals. Particular importance is placed upon an external attribution for the symptoms, and as noted in Chapter 2, independent events might encourage just such an external attributional style. The model by Blackwood et al. (2001) of persecutory delusions is also compatible with a psychosocial stress influence. For example, the attentional bias towards threatening information might be the logical consequence of an unpleasant intrusive event; and the attributional bias involving malevolence may be an unsurprising consequence of being the victim of an intrusive event.

3.9.2 The Effects of Psychosocial Stress on the Normal Population

The effects of psychosocial stress are increasingly being understood in terms of cognitive-affective meaning structures and processes, i.e. themes. It is clear that in the general population the type of psychosocial stress experienced does predict the type of themes that individuals experience in their thoughts. For example, loss events lead to depression, danger events to anxiety, and people who have experienced both events develop both anxiety and depression (Finlay-Jones & Brown, 1981). It is also well established that in post-traumatic stress disorder the type of stressful life event a person has experienced will be found in the themes of their flashbacks and preoccupied thoughts (ICD10, p.148; DSM4, p.424). In the general population psychosocial stress appears able to alter fundamentally people's core beliefs about their own self and the world. The inclusion of the diagnostic category in ICD-10 of 'enduring personality change after catastrophic experience (EPCACE)', is an example of this. Further, people who have suffered similar psychosocial stressors share common cognitive/affective responses (Lebowitz & Newman, 1996). Is there evidence that the type of psychosocial stress influences not only thought processes in the general population, but also the type of themes that appear in the delusions of patients with psychosis?

3.9.3 Experience per se and Psychotic Themes

People's experiences appear to influence their delusional content (Garety & Hemsley, 1994 p.125). The historical and cultural evidence discussed earlier is supportive of this, as is the disorder of Folie a Deux. Behavioural experiments can reduce delusional conviction (e.g.

Fowler et al., 1995), challenging patients' delusional beliefs directly can increase delusional conviction (Milton, Patwa & Hafner, 1978). Morrison (2001) discusses how experience is likely to influence the appraisal of any cognitive intrusions into consciousness.

3.9.4 Prior Concerns and Psychotic Themes

Harrow, Rattenbury & Stoll, (1988) found that 70% of delusional themes in their sample appeared to relate to concerns patients had before they developed psychosis. However, it is not clear whether or not onset was dated accurately and the sample size was small. Also, the concerns appeared to include simple everyday experiences rather than severe psychosocial stress. So the study by Harrow et al., appears to make only low level links between experience and theme development, and they are not necessarily stress-related. More recently, Rhodes and Jakes (2000) found that delusions appeared to relate to patients' fundamental concerns about life, including their goals and their life history. However, the delusional themes could have led to their goal-disruption and the sample was small. Stronger evidence for a psychosocial stress-theme link has come from a steady trickle of case studies in the literature.

3.10 PSYCHOSOCIAL STRESS AND THEMES: DIRECT EVIDENCE

3.10.1 Psychosocial Stress and Theme Formation: Case Study Evidence

Case studies have found links between the economy and economic delusions (Chadwick & Birchwood, 1994; Yorston, 1997), a skin disease and the delusion of being a lizard (Browning & Jones, 1988), and being unmarried and alone and the development of religious delusions (Kingdon & Turkington, 1991). Delusion of pregnancy has been reported after the death of children (Shankar, 1991), male rape (Varma & Katsenos, 1999) and sterility (Griengl, 2000). Concerning the main theme of interest in the present study, persecutory theme, Peter Chadwick (1993) describes how real persecution appeared to play a role in the development of his own first-episode persecutory delusional theme. Fuchs (1999) reported two cases of torture which preceded the development of the Capgras syndrome, the definition of which (SCAN 1.1 manual p.133) meets criteria for a persecutory delusion.

Although case studies linking the type of psychosocial stress to the type of theme continue to appear in the psychiatric literature, they suffer from obvious methodological limitations. These

include lack of generalisability and the absence of rating events for independence. Evidence that is at least more generalisable would come from group studies examining the issue.

3.10.2 Psychosocial Stress and Delusional Theme Formation: Group Study Evidence

Few group studies have directly examined a link between psychosocial stress and the themes in delusions. Those doing so have mainly concentrated on stressful life events, although one study looked at EE. Some studies have examined the effect of one type of event on one type of theme. Others have looked at various themes with various types of events. A notable feature of almost all the results is that they were derived from post hoc analyses and few attempted to make links of a higher psychological order. Most studies have focused on ‘paranoid’ delusions (by which they mean the co-occurrence of reference and persecutory themes together).

(i) Immigration Studies and ‘Paranoia’

Some studies have observed a link between immigration and the development of paranoid symptomatology. Westermeyer (1988) quotes Odegard (1932) who noted a high rate of paranoid symptomatology in immigrants. Murphy (1955) reported similar findings among refugees who became psychiatric patients. However, it is not clear whether ‘paranoid symptomatology’ is the same as a formal persecutory theme. Despite this, these results were replicated by Littlewood and Lipsedge (1981). They found that 50% of Caribbean patients with psychoses in a retrospective London sample had a paranoid theme, significantly higher than their white counterparts.

(ii) Intrusive Events and ‘Paranoia’

On the basis of detailed clinical interviews with paranoid patients, Lemert (1962) concluded that most if not all had been victims of genuine conspiracies. However, in the absence of the precise dating of events and of delusional onset, it is difficult to rule out the possibility that the paranoia had led to the situations in which victimisation was suffered. Two studies that did date both occurrences accurately were Harris (1987) and Day et al. (1987). In these studies, a specific type of life event was linked to the development of psychosis. *Intrusive* events are those that on common-sense grounds would be expected to induce a paranoid feeling in those who experience them. The key components are having personal boundaries intruded upon by another person or organisation that is attempting to interfere or control the person in some

way. Harris (1987) re-analysed the data from the classic Brown and Birley (1968) study. Harris found that about one third of patients with schizophrenia had experienced an intrusive event compared with 3% of the community control group. In the three weeks before onset an intrusive event was 20 times more likely in the schizophrenia group. Day et al. (1987), reporting data from the WHO International Pilot Study of Schizophrenia, found a similar high proportion of intrusive events. However, there are several limitations to these data in attempting to link intrusive events with a persecutory theme. First, not all patients with schizophrenia experience a persecutory theme so the link would only apply to a sub-group. Next, the proportion of cases with a persecutory theme was not specifically examined in relation to the occurrence of prior intrusive events. In addition, both studies only analysed for a link with schizophrenia post hoc, although the rating was blind. The air force study by Beighley et al. (1992) (mentioned in Chapter 2) also supports an intrusive-persecutory link, because all six recruits who developed first episode psychosis experienced a persecutory theme. The issue about prodromal states leading to life events is particularly relevant in the case of intrusive events. This is because a person experiencing a prodrome may induce appropriate attempts to control them by others, and these may be intrusive in quality.

(iii) High EE and Persecutory Delusional Theme

Harris (1991) notes the similarities between intrusive events and the concept of High EE. From this, it might be predicted that patients with psychosis who were living with highly critical carers might be more likely to develop a persecutory theme. Only one study appears to have addressed this issue. Ivanovic, Vuletic & Bebbington (1994) found that patients with a diagnosis of hebephrenic schizophrenia typically lived with carers who expressed more EOI, whereas patients with paranoid schizophrenia lived with those who expressed more criticism. However, the authors point out the cross-sectional nature of the study, which might mean that the paranoid theme could have provoked more criticism from the carer. The authors also acknowledge the small sample size.

3.10.3 Influences on Theme are Compatible

The major lines of evidence on the positive symptoms of psychosis, such as meta-representation, beliefs about the self, attributional style, mood and psychosocial factors are compatible with one another (Garety et al. 2001). They simply appear to be formulated at

different levels of explanation or at different stages in what is probably a long and complex causal chain.

Given the considerable evidence that psychosocial stress plays a role in triggering psychotic relapse (and possibly onset), its role has received surprisingly little attention. Most studies that have directly addressed the 'stress-theme link' issue have suffered from methodological limitations. These include small sample size, failure to date accurately when onset and psychosocial stress occurred, and failure to consider the independence of the stress. Apart from the case studies, no study has used first-episode patients before, which could be important, given the 'lock and key' (e.g. Parker et al., 1998) sensitisation hypothesis. Very importantly, almost all studies have based their conclusions on post hoc analyses.

Most of the links that have been proposed between psychosocial stress and theme are what one would call low-order topographical links. This means the findings lack breadth in their theoretical and clinical application. The only higher-order link proposed has been that between intrusiveness and the development of a persecutory theme.

Given the indirect general evidence, case study material and group studies, there would seem to be a case for exploring psychosocial stress and themes in a methodologically structured way. What appears missing from the literature is a study with the following design features: a large group of first episode participants, accurate dating of psychosis onsets and events, ratings of the independence of events, rating of events contextually, and specific higher order a priori hypotheses about the nature of psychosocial stress-theme links. The study presented in this chapter has sought to include each of these factors in its design.

3.10.4 Do Intrusive Events Influence the Onset of Persecutory Delusions?

In attempting to test whether or not psychosocial stress does influence delusional theme, providing evidence of just one link would be sufficient to support the theory. Whilst there are a variety of event-theme hypotheses which could be tested, in considering all the empirical evidence, the particular hypothesis that has the most empirical backing is that intrusive events influence persecutory delusions. This event type has the design advantage that it is hypothesised to link with only one type of delusional theme: persecutory. Therefore a

persecutory delusion group may be compared with a group of people with non-persecutory delusions without the problem that another theme might confound the results. There is another design advantage of using the intrusive-persecutory hypothesis to test a role for psychosocial stress on delusional themes. This is that there are no other plausible dimensions of psychosocial stress apart from intrusiveness, which might lead to a persecutory theme. The only other type of event with any sort of rationale might be self-esteem reducing events. However, it is argued here that the evidence base is too weak to warrant testing this as an a priori hypothesis using a psychosocial approach, or to necessitate controlling for it statistically in an intrusive-persecutory analysis. First, although two recent cross-sectional studies have found an association between self-esteem and persecutory delusions (Freeman et al., 2001) and paranoid ideation in non-clinical participants (Martin & Penn, 2001), there is no strong evidence that self-esteem is actually causal to the development of persecutory delusions. Secondly, If self-esteem did exert an influence, it more likely only influences a small sub-group of patients (Freeman et al., 1998), perhaps those with 'bad-me paranoia' (Freeman et al., 2001). Thirdly, self-esteem does not discriminate between delusional themes, as it is hypothesised to influence both persecutory and grandiose themes. Fourthly, the self-esteem hypothesis is complicated by the fact that it is a multifaceted construct, and only some (as yet unidentified) domains might play a role (Blackwood et al., 2001). Finally, as noted earlier, a recent review concluded that there is no strong evidence that self-esteem does in fact influence a persecutory theme (Garety & Freeman, 1999).

3.11 SUMMARY OF CHAPTER 3

This chapter has discussed the possibility that the apparently chaotic contents of delusions may be understandable with reference to prior psychosocial stress. The definition, characteristics, and causation of delusions were outlined. The concept of psychotic theme was identified and defined, and its clinical and theoretical importance highlighted. Delusional theme causation was discussed, placing particular emphasis on psychosocial stress, but including other influences too.

Methodological issues were discussed, including the importance of demonstrating that a stressful event is associated with only one theme, and that a theme is associated with only one type of event. In order to test for an event-theme association, the hypothesis with the most

empirical evidence is for intrusive events to influence persecutory delusions. This evidential basis comprises the effect of psychosocial stress on the normal population, the hypothesis' compatibility with major models of delusions, a study involving criticism, patients reported pre-illness experiences and concerns, stressful event case studies, group studies on immigrants, and group studies of intrusive events before psychosis. The design of the planned study, which overcomes many methodological limitations of previous studies, was outlined.

Chapter 4:

Expressed Emotion

4.1 INTRODUCTION

The development and history of Expressed Emotion (EE) is well known and reviewed by George Brown himself (Brown, 1985). The term was introduced by Brown for the third of his studies on the experiences of recently discharged patients living in different types of accommodation (Brown, 1959; Brown, Monck, Carstairs & Wing, 1962; Brown, Birley & Wing, 1972). The motivation to formulate the concept came from the unexpected observation that there was a relatively high rate of hospital re-admission for patients who returned to a relationship with “close ties”. This was refined into a concept called “high emotional involvement” in the second study and further refined into the concept of EE for the third study (Brown, 1985 p.8-9). The ability of High EE to predict relapse is not in doubt (Bebbington & Kuipers, 1994; Parker & Hadzi-Pavlovic, 1990; Butzlaff & Hooley, 1998), and many recent reviews of EE-based family intervention have been very positive (as discussed in Chapter One). However, despite over 40 years of research, the factors which underlie its development and maintenance are still poorly understood. A key next phase of EE research should be to understand its genesis (Wearden et al., 2000; Linszen & Birchwood, 2000).

This chapter discusses in detail factors which have been found to differentiate High from Low EE. Before this, the chapter will summarise the key background issues of EE, particularly during the early phase. These cover what the concept means in general terms, the stability of EE, the prevalence of High EE, the ability of High EE to predict relapse, its status as a cause of relapse and the theoretical and clinical impact of EE research. The chapter also introduces the other main variables that have been used to understand the impact of care on carers of people with psychosis; variables which this study has also included, in an attempt to understand the difference between High and Low EE.

4.2 GENERAL ISSUES OF EE

4.2.1 The Concept of EE

The concept of EE will now be discussed in general terms. EE has been conceptualised in various ways, each placing particular emphasis on the patient, the carer or the circumstances. A few place emphasis on the patient, for example, EE as a chronic stressor for the patient (Brown et al., 1972). A few emphasise the carer, for example EE as a method by which carers cope with the stress caused by the patient's illness (e.g. Greenley, 1986; Flannagan, 1998; Barrowclough & Parle, 1997). Most conceptualisations, however, emphasise the situation between carer and patient as a whole. Examples include EE as referring more to an environment than a person (e.g. Nuechterlein et al., 1994), as analogous to the 'blood pressure' of family life (Kuipers, 1994), as a snapshot of ongoing patient-carer transactions (Smith, Birchwood, Cochrane & George, 1993), as a measure of carers' appraisal of their circumstances indicating the quality of the relationship between patient and carer (Scazufca & Kuipers, 1996), and as a 'thermometer' of the process of carer and patient adjustment to the psychosis (Birchwood, 1999).

4.2.2 What is the Relationship between High and Low EE?

Although studies have found various differences between carers rated High and Low EE, it should be noted that the two groups overlap with each in various ways, including needs (e.g. Smith et al., 1993) and attributional style (e.g. Brewin et al., 1991). It seems that Low EE is not simply the absence of High EE, but confers extra protection from relapse of itself (e.g. Bebbington & Kuipers, 1994). EE, or at least CC, appears to exist on a continuum rather than representing two qualitatively different groups of people (Shimodera, Inoue, Tanaka & Mino, 1998; Moore et al., 1992).

4.2.3 How Stable Is EE?

The stability of EE is an important issue since if factors can be correlated with change in EE, determinants of the phenomenon may be isolated. Many studies show that EE can change naturally over various periods of time (e.g. Brown et al., 1972; King et al., 2000; McCreadie, Robertson, Hall & Berry, 1993), mainly in the High to Low direction (e.g. Brown et al., 1972). Other studies show it can be lowered or raised in response to intervention (e.g. Leff et al.,

1982; Telles et al., 1995). Predictors of the persistence of EE components include the past level of EE (King et al., 2000), higher face-to-face contact, carer employment status and burden (Boye et al., 1999). However, the Boye et al. study used a high number of exploratory tests with no accompanying statistical correction, so its findings require replication using a priori hypotheses.

4.2.4 How Stable Is EE In The Early Course?

There appear to be six studies which have reported early EE levels and then also reported EE levels at follow-up (Huguelet et al., 1995; Stirling et al., 1993; Leff et al., 1987; Rund, Oie, Borchgrevink & Fjell, 1995; Jarbin, Grawe, & Hansson, 2000; Patterson et al., 2000). Early EE (High v Low) is able to change naturally over a follow-up period of at least seven months (Jarbin et al., 2000), nine months (Patterson et al., 2000), 12 months (Leff et al., 1990), and 18 months (Stirling et al., (1993). One small uncontrolled study found that it could be lowered in response to intervention (Rund et al., 1995). Another study measured EE once a year over five years and found that 86% of carers had the same EE status between years one and five (Huegelet et al., 1995). However, the study does not report if there were changes in the intervening years. The bulk of early EE instability appears to be accounted for by changes from High to Low EE (e.g. Leff et al., 1990) or High CC to High EOI (Stirling et al., 1993; Patterson et al. 2000).

4.2.5 How Prevalent Is High EE?

The aggregate analysis of Bebbington and Kuipers (1994), which included both epidemiological and non-epidemiological studies, revealed that 52.4% of carers in EE relapse studies were High EE. The frequency of the High EE components has varied widely across studies. Some have found little EOI (e.g. Macmillan, Gold, Crow, Johnson, & Johnstone, 1986 found 4%) whereas others have found a much higher proportion (e.g. Stirling et al., 1991 and Martins et al., 1994, both found 45%). A study by McCreadie and Robinson (1987) used an epidemiological design and found that 58% of patients with a carer were in a High EE relationship with them, which comprised 21% of all patients in the district.

4.2.6 How Prevalent is High EE in the Early Phase of Psychosis?

The prevalence of High EE during early psychosis is variable, though on average is found to be very similar (at 56.5%) to later in the course when six first episode/admission/early onset samples are aggregated (Wig, et al., 1986: Denmark 54%, Chandigarh 23%; Huguelet, Favre, Binyet, Gonzalez & Zabala, 1995: 65%; Linszen et al., 1996: 62%; Stirling et al., 1993: 48%; Nuechterlein, et al., 1992b: 60%; Patterson et al., 2000: 61.5%,).

4.3 EE AND RELAPSE

4.3.1 EE as a Predictor of Relapse

Predicting risk is one of the central concerns of the clinician, and EE has the potential to be extremely useful in this respect. Statistical estimates of the increased relapse rate for patients with psychosis discharged into the care of a High EE carer during the nine months after hospitalisation have been 3.7:1 (Parker & Hadzi-Pavolic, 1990), 2.5:1 (Bebbington & Kuipers, 1994), and 1.86:1 (Butzlaff & Hooley, 1998). EE's predictive ability has been shown to be independent of medication (Bebbington & Kuipers, 1994), higher contact with High EE carers increases predictiveness (Bebbington & Kuipers, 1994), and the predictive effect operates for as long as eight years (Tarrier et al., 1994; Monking, Hornung, Stricker & Buchkremer, 1997). Criticism appears to be a more reliable predictor of relapse than High EOI (Bebbington & Kuipers, 1994). A stable High-High or a Low-High EE pattern is more predictive of relapse than a Low-Low or a High-Low level (Boye et al., 1999).

4.3.2 Relapse Variance EE Does not Explain

Although EE is a powerful and robust relapse predictor, there is still a large proportion of variance that it is unable to account for, particularly during the early phase. These reasons include less than optimal inter-rater reliability rating scores (Bentsen et al., 1996a; Bentsen et al., 1996b), and the interactions between EE, stressful life events and medication (discussed in Chapter 1).

4.3.3 Relapse - Predictiveness of EE During the Early Phase

The ability of High EE to predict relapse early in the course of psychosis and the size of the effect compared to later in the course has been an issue of debate. Of the 10 main studies to

examine the issue, four have found that it did not predict relapse (Stirling et al., 1993; Huguelet et al., 1995; Monking et al., 1997; Jarbin et al., 2000) and six have found that High EE or one of its components did predict relapse (Macmillan et al., 1986; Leff & Brown, 1977; Neuchterlin et al., 1992; Barrelet et al., 1990; Linszen et al., 1997; Leff et al., 1990). It seems that although early High EE can predict relapse, it does so less reliably and with a smaller effect size than later in the course (Butzlaff & Hooley, 1998; Leff & Brown, 1977).

4.3.4 Does High EE Actually Contribute To Relapse?

If High EE were a stressor, and a mechanism was found for its action on relapse, then the case for High EE being causal to relapse would be strengthened. Evidence for High EE being a stressor on patients comes from results relating to face-to-face contact (Bebbington & Kuipers, 1994), medication and stressful life events (Leff & Vaughn, 1980), successful family intervention studies (as discussed in Chapter One), direct interaction studies (e.g. Simoneau, Miklowitz & Rakhshanda, 1998), and the perception of patients themselves (Cutting & Docherty, 2000; Scazufca & Kuipers, 2001). However, the relationship between High EE and relapse might be confounded by other factors, such as longer DUP (e.g. Macmillan et al., 1986; Patterson et al., 2000), cannabis use (Linszen et al., 1997) or medication non-compliance (Phaorah et al., 1999). Also, no mechanism has been found for EE to cause relapse, despite plausible theories (e.g. Kavanagh, 1992; Tarrier & Turpin, 1992). In summary, the weight of evidence is that EE probably does contribute to relapse but there is no definitive evidence and some of the effect might be due to other factors.

4.4 THE IMPORTANCE OF EE

Now that several aspects of EE have been reviewed, it is possible to evaluate its theoretical and clinical significance.

4.4.1 Theoretical Impact of EE Research

The powerful and consistent ability of High EE to predict relapse together with the evidence that other forms of stress appear to influence symptoms (as discussed in Chapter 2), led to the development of a new framework to understand the disorder (Zubin & Spring, 1977). From this important insight Nuechterlein et al. (e.g. 1994) have developed a framework to encompass a wide variety of inter-relationships between psychosis and the bio-psycho-social

environment. EE research has also highlighted the importance of social factors in psychosis, which for many years were thought to be of little relevance. It has also contributed to the development of frameworks to understand carer need (Fadden, 1998). The role High EE might play in the initial onset has been under-researched, partly because of a wish not to add to a culture, now discredited, of blaming families for the illness.

4.4.2 Clinical Usefulness of EE Research

EE is relevant to family interventions for psychosis in a number of ways. Their development has been stimulated by EE research. They have often aimed to lower EE in order to reduce relapse, and the interventions suggest factors which influence the development and maintenance of High EE. In addition, research has identified that some staff are in High EE relationships with the patients they care for (e.g. Moore et al., 1992; Tattan & Tarrier, 2000). As noted earlier, many recent papers have reviewed the results of family intervention studies and found the approach to be of great value at reducing relapse. In addition to reducing relapse, there is some evidence that family intervention is able to improve patient social functioning (Penn & Mueser, 1996; Lenoir et al., 2001) and reduce carer burden (Cuijpers, 1999; Stam & Cuijpers, 2001). However, family intervention needs to be continued for positive effects to be maintained (Kuipers et al., 1999). Also, many studies suffer from a range of methodological weaknesses such as inadequate experimental blindness, reliability of outcome measures, failure to correlate changes in EE with relapse, and the general absence of intention to treat analyses (Barbato & D'Avanzo, 2000). Improved understanding of the nature of EE may identify key targets to lower EE and relapse rates more effectively and efficiently.

Gleeson et al. (1999) states that family interventions developed for later in the course need to be adapted to be effective at the first episode. Indeed, the early intervention study by Linszen et al. (1996) showed that EE can be unintentionally raised. Of the five early intervention studies that Gleeson (1999) reviews, only two involved EE and the evidence base for early EE-based family interventions is yet to be established. Although there have been few early family intervention studies published (Larsen et al, 2001), there are currently many trials underway (as described in abstracts in the September 2000 edition of *Acta Psychiatrica Scandinavica*). The rationale for the approach is compelling because the first episode may be a critical period which

influences the long-term relationship between the patient and carer. Understanding early EE may help interventions to foster beneficial relationships for both.

4.5 IMPACT OF CARE ON THE PEOPLE WHO CARE FOR PEOPLE WITH PSYCHOSIS

The present study investigates the difference between High and Low EE, including the relevant attributes of carers. This will include an assessment of the relationship between various carer 'needs' (e.g. burden) and EE, and will be discussed in detail later in the chapter. The final section of this chapter therefore introduces the key variables which have been used to understand the impact of care on carers of people with psychosis. Impact of care at the first episode of psychosis is a neglected research area, with the Scottish Schizophrenia Research group (1987) claiming that they were the first to examine the issue.

4.5.1 Emotions, Distress and Depression

Carers experience a range of emotional reactions such as anger, grief, guilt, and rejection (e.g. Kuipers & Bebbington, 1994). Severe emotional reactions at the first episode, particularly loss (Patterson et al., 2000), may be prevalent, although this may be delayed (Birchwood & Smith, 1987). In terms of the prevalence and severity of distress, a substantial number of carers of people with psychosis experience a high level of personal distress, with 60.3% meeting GHQ case criteria (Barrowclough, Marshall, Lockwood, Quinn & Sellwood, 1998). The SSRG (1987) found that 77% of carers were GHQ-distress 'cases' at the first episode. In contrast, a recent study found that only 12% of first episode carers were GHQ cases (Tennakoon et al., 2000), although the difference may be due to using different GHQ versions and case 'cut-off' points. A significant association has been found between carer depression and illness chronicity (Barrowclough et al., 1998). Carer depression at the first episode is an under-researched area.

4.5.2 Burden

Burden can be defined as the difficulties and problems suffered by a carer due to caring (Platt et al., 1985). Subjective burden is commonly used to cover a broad range of negative feelings and emotions such as guilt, uncertainty, ambivalence, hate, anger, antipathy and feelings of loss. Burden of the caregivers of people with psychosis has been well documented (Szmukler et al., 1998; Magliano et al., 1998a.), and may be severe in a variety of areas (Kuipers &

Bebbington, 1994). A population-based survey of carers' subjective burden found that 50% were dissatisfied with their caring role (Szmukler et al., 1998).

At the first episode, burden may emerge as problems with patient individuation from the carer become more evident over time (Gleeson et al., 1999). At this time, carers are already experiencing a variety of burdens (Tennakoon et al., 2000).

4.5.3 Coping

Carers vary widely in their responses to coping with psychosis. Carer coping can be conceptualised in many different ways, including as a personality characteristic (e.g. Bentsen et al., 1998a), as a situational response to a given behaviour, or as a style (e.g. Birchwood & Cochrane, 1990). The advantage of assessing by style is that it does not generate an endless list of individual strategies (Flannagan, 1998), yet is not so broad that it cannot differentiate between carers. Coping activity changes over time (Pearlin & Schooler, 1978), illustrated in a follow-up study by Scazufca and Kuipers (1999), who found that coping strategies were used more frequently at inclusion than at re-assessment. In the Scazufca and Kuipers (1999) study avoidant coping seemed less effective at regulating the distress of care-givers than problem-focused strategies. At the first episode carers are already attempting to use a variety of strategies (Tennakoon et al., 2000). Birchwood and Cochrane (1990) found that carers' of less than two years experience had already adopted broad styles of coping that were applied with considerable consistency across situations.

In conclusion, the impact of care on the carers of people with psychosis appears to involve a range of overlapping, clustered, interconnected and reciprocal outcomes (Barrowclough et al., 1997). Lazarus and Folkman's (1984) appraisal model is increasingly being employed to understand carer reactions (e.g. Provencher, Fournier, Perrault & Vezina, 2000). There has been little work done on carer need at the first episode and no study has so far examined how carer needs might relate to EE at the start of the illness.

4.6 FACTORS THAT LINK WITH EXPRESSED EMOTION

This section discusses the factors that have been found to be correlated with EE both generally and during the early phase of psychosis. Key methodological issues are outlined before

discussing EE correlates. In line with the main hypothesis of the EE study – that carer appraisal variables will be both associated with EE status and be stronger independent predictors of it than patient illness-related factors – the review emphasises these two classes of correlate. After this, the merits of analysing individual EE components are argued and a recently proposed framework to explain High EE causation is discussed. The possible clinical and theoretical implications of the present first episode EE correlate study are also outlined.

4.6.1 Methodological Issues in EE Correlate Research

An extensive array of variables have now been tested for their association with EE. Gleeson et al. (1999) makes three general points about the EE literature. First, samples have often been small and so many studies have lacked statistical power, and therefore only tentative interpretations of the results can be made. Secondly, there are few follow-up studies of EE, so most studies demonstrate association rather than potentially allowing causal interpretations. Thirdly, samples have nearly always been based on convenience rather than representative of carers as a whole. In addition, an increasing number of studies are using instruments other than the CFI (e.g. Harrison & Dads, 1992; Wuerker, 1996), despite the fact that such measures tend to miss a proportion of High EE carers (e.g. Kazarian, 1992). This makes measurement less precise and the results less reliable. Most studies have only tested a small number of variables and used univariate statistics, rather than examined a range of potential correlates using multivariate statistics to control for ‘nuisance’ variables. The bulk of studies have only used the overall High versus Low EE classification rather than analysed EE components with potential correlates, which limits the specificity of the findings.

An important design issue which is neglected in the literature is the implications of carers being High EE on more than one component of the measure (i.e. showing ‘High-EE co-morbidity’). Even comprehensive reviews of EE fail to address the issue (e.g. Wearden et al., 2000). Carers are often rated high on more than one component of EE, including those who are both High CC and High EOI (e.g. Barrowclough & Tarrier, 1990: 34%; Harrison & Dadds, 1992: 40%), as well as carers who are high on all three components (e.g. Barrowclough, Tarrier & Johnson, 1996: 30%; Barrowclough & Parle, 1997: 19%). The vast majority of the hundreds of papers which used only an overall High versus Low EE classification do not report this information. Even studies which examine individual components of EE usually neglect to report it. For

example, in a series of papers the Bentsen group analyse correlates of EOI (Bentsen et al., 1996a), CC and H (Bentsen et al., 1998c), and test locus of control (Bentsen et al., 1997), guilt (Bentsen et al., 1998a) and 'stress' (Boye et al., 1999) as correlates of EE components without ever stating what proportions of carers had High EE co-morbidities. The issue is important because of the possibility that being High on more than one component might impact on the relationship between EE and potential correlates. However the issue is very rarely discussed in the literature, although Bentsen et al. (1996a) do acknowledge that there could be interaction effects, in that predictors of EOI might vary depending on the presence of criticism or warmth (p.629). Thus in many papers, it is not possible to know if 'significant' correlates of an EE component are 'significant' because of the component itself or another High EE component or a combination of the two. Thus by presenting the data relating to EOI and CC/H in two separate papers (Bentsen et al., 1996a; Bentsen et al., 1998c), it is not known to what extent being High EOI might have impacted on the relationships found between High CC and the explanatory variables (in Bentsen et al., 1998), nor what impact being High CC might have had on the variables identified as correlates in the EOI paper.

One way of addressing the problem is to recruit a very large sample of carers in order to obtain a sub-sample of carers who are only High EE on one component. This would provide a definitive test of whether a variable was associated with a particular component. In practise, this might be possible for High CC and High EOI, but H so commonly appears with High CC that it may be unfeasible for that component. A variant of this type of approach was used by Barrowclough and Tarrier (1990) who had a sample including 53 High EE carers and 19 Low EE carers. The study found that High EE carers judged patients to have significantly lower social functioning than Low EE carers. In order to tease out which component(s) might be responsible, scores of different combinations of High EE were descriptively compared. Even though H never appeared alone, by comparing scores for the H plus CC group, with the CC alone, and H plus CC plus EOI groups, it appeared likely that H was the component which was associated with the lowered perception of social functioning. An extension of this approach, which does not seem to have been used in the literature, might be to run partial correlations on EE scores as continuous variables controlling for the possible effect of other components.

The second design issue stemming from High EE co-morbidity is the choice of within-sample comparison groups. Some studies have used a design which compares carers High on an EE component with all the other carers who are Low on that component, which includes a mixed group of people who may be Low EE and others who may be High EE on a different component. Examples include studies on EOI correlates (Bentsen et al., 1996a) CC/H correlates (Bentsen et al., 1998c); locus of control (Bentsen et al, 1997; Hooley, 1998), and guilt (Bentsen et al., 1998a). The problem with this design is that it tends to obscure differences between each High EE component and carers who are Low EE across the three measures. In contrast, some studies have used a design which involved comparing groups of carers who are High on an EE component, with the Low EE carer group (e.g. Brewin, MacCarthy, Duda, & Vaughn, 1991; Barrowclough & Tarrier 1990). This provides a more clear-cut differentiation between the High and Low groups.

To summarise the issue of High EE co-morbidity, very few studies report the EE co-morbidity proportions, and even fewer attempt to tease out the possible impact co-morbidity might have on each component's relationship with the predictor variables. Some studies' results are also made potentially less clear-cut because of using a mixed High and Low EE comparison group. Therefore, the literature at present can identify factors which are associated with overall EE, but there is less certainty about the results concerning EE component relationships. This lack of precision should be borne in mind during the review of studies which have found EE correlates.

4.6.2 Factors other than Carer Appraisal and Patient Illness-Related Characteristics that Link with EE

This section summarises the main factors found to correlate with EE which are not the primary focus of the present study.

(i) Cultural Factors

Cultural factors are implicated in EE genesis because cross-cultural studies show that EE component distributions, and the inter-relationship between components, differs according to geographical location (e.g. Wig et al., 1987b). Cultural factors may influence EE through carer

attributions about illness (e.g. Jenkins & Karno, 1992) and family structure (e.g. Weisman, 1997; Kurihara, Kato, Tsukahara, Takano & Reverger, 2000).

(ii) Patient factors

Many patient socio-demographic variables have been tested in relation to EE and the few associations found offer little insight into the genesis of High EE. The adjustment of patients before the onset of psychosis has been examined with contradictory results (e.g. Stirling et al., 1991; Linszen et al., 1997). Associations have been found between different High EE components and patient coping style (Bentsen et al., 1996a; Rosenfarb et al., 1999) and illegal drug use (Huguelet et al., 1995; Bentsen et al., 1996a ; Linszen et al., 1996; Lopez, Nelson, Snyder, & Mintz, 1999).

A consistent association has been found between High EE and ‘difficult’, ‘problematic’, ‘bothersome’ ‘disturbed’ behaviour or ‘unco-operative’ behaviour (e.g. Brown et al., 1972; Smith et al., 1993; Barrowclough et al., 1997; Bentsen et al., 1998c; King, 2000). Content analyses of staff criticisms are also consistent with this relationship (e.g. Moore et al., 1992). Whilst High CC and H seem to be consistently associated, High EOI may not be (e.g. Bentsen et al., 1996a). Where more than one carer is involved, EE status will not necessarily be the same for both. Interestingly, the relationship is much stronger when carers rather than investigators make the behavioural judgement (e.g. Bentsen et al., 1998c).

The social functioning of patients after the onset of psychosis has been associated with EE in several studies. King (2000) points out that any relationship is likely to be complex because social functioning comprises a wide repertoire of behaviours, some of which may be important but not others. King also notes that the nature of the relationship between social functioning and EE may also be different depending on the component of EE. A uniform association between lower social functioning and High EE is unlikely because of the idiosyncrasies of carers’ appraisals of patient behaviour. In addition, EE might have a curvilinear relationship, with an ‘optimal’ level of EE increasing social functioning, while Low EE and High EE might both exert a negative effect (King & Dixon, 1995).

Several studies have found that patients who live with High EE carers have a lower social functioning (e.g. Brown et al., 1972; Otsuka, Nakane & Ohta, 1994; Smith et al., 1993; Mavreas, Tomaras, Karydiv, Economou, & Stefanis, 1992; Rund, 1994), although not all studies have found a difference (e.g. Montero, Perez & Gomez-Beneyto, 1998). Young adults early in the course of psychosis do have considerable limitations in the area of social functioning (Lenoir et al., 2001), and an association with EE has also been found during the early course. In the first admission sample of Huguelet et al. (1995), patients with High EE carers had poorer psychosocial adaptation and more maladjustment from the third year onwards to the fifth. Some studies found that particular components of EE, such as EOI, form the primary relationship with social functioning (e.g. King & Dixon, 1995; Mavreas et al., 1992) or Hostility (Barrowclough & Tarrier, 1990). Areas of social functioning that are particularly associated with EE include independent functioning (Smith et al., 1993; Barrowclough & Tarrier 1990), interpersonal functioning (Barrowclough & Tarrier, 1990) and recreation (Smith et al., 1993).

Most studies testing an association between EE with social functioning have been cross-sectional, but the results have been strengthened by follow-up data in a few studies over periods of nine months (Scazufca & Kuipers, 1998; King & Dixon, 1996; Inohue, Tanaka, Shimodera, & Mino, 1997) or two years (Hogarty et al., 1988). Intervention studies also support a relationship between lowered EE and improved social functioning (Penn & Mueser, 1996). It is possible to argue that the direction of effect between EE and social functioning goes either way, but it seems much more likely that a reciprocal interactive process occurs between the two (Inohue et al., 1997; Barrowclough & Tarrier, 1990). The strongest association between social functioning and EE is found when it is carers who make the judgement (e.g. Barrowclough & Tarrier, 1990; Smith et al., 1993; Scazufca & Kuipers, 1996; Scazufca & Kuipers, 1998).

Therefore some types of patient behaviour have been found to be associated with EE, but this may vary with the component of EE, and the relationship is strongest when it is the carer who is judging the patient behaviour.

(iii) Carer factors

Few carer socio-demographic variables have been found to be associated with any consistency with EE across studies. Those that have, such as the links between EOI and being a mother (Miklowitz, Goldstein & Falloon, 1983; Martins et al., 1994; Otsuka, et al. 1994; Bentsen et al., 1996a), seem to offer only distal and indirect clues about EE causation.

(iv) Carer-patient Interactional Factors

Correlates of EE have been identified in direct interaction studies between patients and carers. Most such studies have focused on the carer and a few have focused on the patient. Direct interaction studies and qualitative observations of CFI interviews have revealed that High EE is associated with the carer being more critical (Miklowitz et al., 1984), less supportive (Miklowitz, Goldstein, & Doane, 1989) and more intrusive (Hahlweg et al., 1989), particularly in the case of High EOI carers (Miklowitz, Goldstein, Falloon, & Doane, 1984; Strachan, Leff, Goldstein, Doane, & Burt, 1986). High EE carers are also more unpredictable (MacCarthy, Hemsley, Shrank-Fernandez, Kuipers, & Katz, 1986), talk more and have poorer listening skills (Kuipers, Sturgeon, Berkowitz, & Leff, 1983). They attribute undesirable behaviour to the patient rather than the illness (e.g. Leff & Vaughn, 1985), make more negative statements (Simoneau et al., 1998), and show less flexibility and more co-ercion and vigilance. In contrast, Low EE carers report tailoring their responses to the patient more than High EE carers (Hubschmid & Zemp, 1989). High EE staff have been found to have relationships with their patients that were characterised by less tolerance, inappropriate expectations of patient progress, and frustration (Moore et al., 1992). Patients with High EE carers have been found to make fewer statements of autonomy and more statements of criticism toward the carer (Strachan, Feingold, Goldstein, Miklowitz & Nuechterlein, 1989).

Results of several direct interaction studies suggest that High EE is characterised by a reciprocal negativity between patient and carer (Cook, Strachan, Goldstein & Miklowitz, 1989; Simoneau et al., 1998). There is a tendency for conflict to escalate if it is generated (e.g. Hubschmid & Zemp, 1989), for longer negative sequences of non-verbal behaviour (Hahlweg et al., 1989), and for repetitive negative verbal interchanges of up to three volleys (Simoneau et al., 1998). Wuerker (1996) describes High EE families of patients with schizophrenia as more tightly joined. There are marked differences in control patterns, with a family system that

combines over-responsiveness with conflict about who is in charge. Power, it is suggested, is much less of an issue in Low EE families.

Kavanagh (1992) describes the reciprocal sequences between patient and carer as 'destructive feedback loops'. This fits with the notion of a transactional model of EE development. Birchwood and Smith (1987) suggested that High EE may develop through a sequence of developmental interactions or transactions between patient and carer. Carers are hypothesised to use coping to improve their perceived control over the patient's disturbance or at least to reduce their exposure to it. Factors that are thought to influence the transaction are the nature and severity of patient disturbance, the construing of this as a 'problem' and the ensuing stress, concern and intra-familial tension. High EE is seen as synonymous with coping failure. The model provides a broad framework within which to place the individual findings of the various direct interaction studies discussed earlier. It seems to predict that a full understanding of EE will only come from studying patient, carer and situational factors, and how they interact over time. However, this may not mean that all three factors are necessarily equally important. The major psychological models of emotion point to the primary importance of cognitive appraisal over objective circumstances in the generation of emotion (as reviewed by Strongman, 1996). Therefore, it might be expected that whilst all three types of influence might contribute to EE status, carers' appraisal of their situation would typically be the strongest determinant. Although the direct interaction studies have not yet included a longitudinal element, the reciprocal negativity they illustrate is important because it suggests how EE might develop over time, in line with the transactional model of EE development.

4.6.3 Patient Illness-Related factors associated with EE

A range of illness-related variables have been tested with EE, including diagnosis, symptom severity, symptom type, speed of onset, number of admissions, age of onset, illness length, duration of untreated psychosis, sub-clinical psychopathology and cognitive deficits.

(i) Symptoms and EE

Associations between EE and various symptom-related attributes have generally been non-significant, or when significant, have lacked consistent replication. The sub-type of psychosis is not important (e.g. Linszen et al., 1997), although in one small study patients with paranoid

schizophrenia were cared for by carers with higher criticism whereas patients with hebephrenic schizophrenia were with carers who scored higher on EOI (Ivanovic et al., 1994). Symptom severity has not usually been found to be associated with EE (e.g. Vaughn & Leff, 1976a; Brown et al., 1972; Vaughn et al., 1984; Karno et al., 1987), although some studies have found more symptomatology in the High EE group, when assessed by a researcher (e.g. Glynn et al., 1990; Bentsen et al., 1998c). Some studies have found an association between symptom type and EE. Some have found a relationship between positive symptoms and EE but not negative symptoms (e.g. Glynn et al., 1990; Shimodera et al., 1998), whereas others have found a relationship with both (e.g. Ivanovic et al., 1994; Bentsen et al., 1998c). Still others have found that criticism was rarely directed at positive symptoms but did focus to a certain extent on negative symptoms (e.g. Moore et al., 1992; King, 2000). King (2000) found that negative symptoms preceded the development of criticism in a follow-up study, although the results were not replicated at a third assessment point. A recent study of EE in care managers of long-term psychosis patients failed to find any relationship between symptoms and EE (Tattan & Tarrier, 2000). Instead, EE was associated with individual case managers.

(ii) Other associations between aspects of the patient's illness and EE

High EE has been found to be associated with greater patient sub-clinical psychopathology (SCP), both verbally (Rosenfarb, Goldstein, & Nuechterlein, 1995) and non-verbally (Woo, Goldstein, & Nuechterlein, 1997). There is likely to be a complex two-way relationship between SCP and EE (Goldstein, Rosenfarb, Woo, & Nuechterlein, 1994), in line with a transactional model of EE development.

High EE is associated with a longer DUP (e.g. MacMillan, et al.; Patterson et al., 2000). There have been mixed findings between EE components' association with a slower speed of illness onset (Hugulet et al., 1995; Stirling et al., 1991; versus Linszen et al., 1997), an increased number of hospital admissions (e.g. Mavreas et al., 1992; Bertrando et al., 1992 ; Bentsen et al., 1996a and 1998c; Shimodera et al., 2000; versus Miklowitz et al., 1983; Tanaka et al., 1995; Barrowclough et al., 1998), and neuropsychological functioning (Rund et al., 1995; versus Bentsen et al., 1998).

The lack of clear and consistent associations between illness-related factors and EE prompted Vaughn (1989) to conclude that differences between High and Low EE lie not with the patients but with the carers, as they differ markedly in how they view the objective condition of the patient.

4.6.4 Carer Appraisal-Related factors associated with EE

EE itself usually appears to be nearer a 'state' (i.e. a response to current situational factors) than a 'trait' (i.e. a response characteristic of the carer relatively independent of the particular situation). For example, carers may display High EE toward one person but not another (Schreiber, Brier, & Pickar, 1995). Also, a carer may use quite different attributional styles for positive and negative symptoms (Harrison & Dads, 1992; Provencher & Fincher, 2000). The 'trait' versus 'state' issue is probably a false dichotomy and it is more likely that carers should be seen as on a continuum between two extremes, with both stable and fluctuating factors exerting an influence.

(i) Personality, Attributions, Empathy, Attitudes

EE has been found to be associated with certain (trait) personality variables. Higher EOI has been associated with increased guilt-proness (Bentsen et al., 1998a) and the chance dimension of Locus of Control (LOC) (Bentsen et al., 1998b). Higher criticism has been found to be associated with the powerful others dimension of LOC (Bentsen et al., 1998b). Differences in other dimensions of attribution style have also been found between High and Low EE carers (e.g. Weisman, Nuechterlein, Goldstein & Snyder, 1998; Hooley & Licht, 1997; Brewin et al., 1991; Brewin, 1994). The most consistent finding across studies has been that highly critical carers perceive negative behaviours of the patient as being more under the patients own control than did Low CC carers (e.g. Weisman, Lopez, Karno, & Jenkins, 1993; Brewin et al., 1991; Moore et al., 1992; Harrison & Dadds, 1998). The other two dimensions that are most associated with CC or H have been internality (e.g. Brewin et al., 1991) and universality (e.g. Brewin, 1994). In line with Hooley's (1987) model, Low EE and High EOI carers make similar attributions of controllability, universality and internality (Brewin et al., 1991). Provencher and Fincham (2000) recently extended the discussion by connecting carer attributions about the patient to notions of cause, responsibility and blame, although studies on EE using this approach have not yet been undertaken.

Other carer appraisal factors associated with EE include lower empathy (Giron & Gomez-Beneyto, 1998; Hooley & Hillier, 2000), higher norm-favouring and less flexible attitudes (Hooley & Hillier, 2000), and a more negative self-concept than Low EE carers (Hooley & Hillier, 2000; Docherty et al., 1998).

Thus a case could be made that certain personality and attributional style factors might predispose carers to developing High EE attitudes, although they could also simply be features of EE itself. Longitudinal studies examining the temporal sequencing between the two could unravel the nature of the relationship.

(ii) Carer Needs, Psychopathology and EE

Some studies have looked at the differing needs of High and Low EE carers. Smith et al., (1993) found that two-thirds of High EE carers, as opposed to one third of Low EE carers, had high levels of need in one or more of the following areas: knowledge about schizophrenia, subjective burden, personal stress, behavioural disturbance and perceived coping. No Low EE carer had high needs on all five criteria and there were about twice the number of High EE as Low EE carers with significant needs. Extending this study, Barrowclough et al. (1998) found that High EE carers also had more clinically important unmet needs.

It has often been suggested that aspects of carer psychopathology, in the form of depression, distress and other affective responses are associated with High EE. Depression was not associated with EE in the follow-up study of Scazufca and Kuipers (1998), and Barrowclough et al. (1996) found that it was only associated if all three EE components were High. In terms of distress and EE, staff-patient relationships that were stressful for staff were associated with higher levels of criticism (Moore et al., 1992). Distress (as measured by the General Health Questionnaire) has been associated with the overall EE classification in one follow-up study (Barrowclough & Parle, 1997). Distress has been found to correlate with EOI but not CC or H in one cross-sectional (Shimodera et al., 1996) and one follow-up study (Boye et al., 1999). Boye et al. suggest that High EOI could be linked to a 'stress response syndrome', which is consistent with Birchwood and Smith (1987) who suggested that grief and unresolved emotions may drive EE. Thus some aspects of carer psychopathology can be associated with EE.

(iii) Carer Burden and EE

Objective and subjective burden has been associated with EE in carers in four cross-sectional studies (Jackson, Smith & McGorry, 1990; Smith et al., 1993; Scazufca & Kuipers, 1996; Bogren, 1997), while subjective burden was associated in two others in which objective burden was not assessed (Bentsen, et al., 1998; Lenior, Dingemans, Linszen & Schene, 2000). Subjective burden also appears to be associated with EE over time, as shown by two follow-up studies (Scazufca & Kuipers, 1998; Boye et al., 1999). Bogren (1997) found that only critical and hostile carers reported more burden. As noted earlier, the subjective appraisal area of 'difficult behaviours' has been associated consistently with High EE (e.g. Bentsen et al., 1998c). Carer burden also predicts higher EE at follow-up (Bentsen et al., 1999). In a related vein, coping styles that are conceptually similar to High EE behaviour (e.g. 'criticism/coercion', 'over protectiveness', and 'emotional over involvement') have been found to be associated with higher burden (Budd, Oles, & Hughes, 1998). In family intervention studies, lowered EE has been associated with lower burden (Penn & Mueser, 1996). It has been suggested that burden could be a mediating variable between stress and EE, such that burden motivates individuals to reduce it, and EE can be seen as a way of coping (Scazufca & Kuipers, 1996). The two concepts may both be facets of caregivers' appraisal but they differ in the type of information they produce. While EE gives a picture of the quality of the relationship between patients and relatives, the burden measure relates to the areas of family life most affected by the presence of the patient, and the distress that carers feel (Scazufca & Kuipers, 1996). If EE reflects carer appraisal, subjective burden may be a more direct mediator than objective burden.

(iv) Carer Coping and EE

Some theories have suggested coping as a determinant of EE. For example, Kuipers and Bebbington (1988) suggested three groups of carers: consistently Low EE who cope well; consistently High EE who cope poorly; and carers who fluctuate in coping effectiveness and therefore EE status depending on the stress upon them. Leff and Vaughn (1985) suggested that flexibility of coping may distinguish High and Low EE carers. Others view EE itself as a coping strategy (e.g. Greenley, 1986; Flannagan, 1998). However, empirical data have been scarce. High EE carers do seem to cope less effectively than Low EE carers (Kuipers et al., 1983; Harrison & Dadds, 1992).

Of the various types of coping, avoidant coping has been associated with EE in a cross-sectional study on dementia carers (Bledin, MacCarthy, Kuipers, Kuipers & Woods, 1990) and also in carers of people with psychosis (Scazufca & Kuipers, 1996; 1999). Although changes in avoidant coping scores over a nine-month follow-up were not significantly associated with EE status at follow up, this could have been due to sample attrition (Scazufca & Kuipers, 1999). Since avoidant coping is typically used when a stressor is appraised as exceeding coping resources (Lazarus & Folkman, 1984), this suggests that High EE could indeed be seen both as a 'failed' way of coping and as the consequence of a lack of other effective coping abilities.

(v) Carer Loss-Appraisal and EE

Evidence that High EE carers feel that they have experienced more loss at the first episode of psychosis has recently been found in a follow-up study (Patterson, Birchwood & Cochrane, 2000). Specifically, High EOI carers experienced more loss than Low EOI carers, High CC carers experienced less loss than those Low in CC, and carers who changed from having High EOI to High CC showed reduced loss. Patterson et al. interpret their results within an attachment framework, arguing that High EE may be driven by loss. Initially, loss may drive High EOI, but if the patient does not return to normal then criticism may evolve over time. Such a process is consistent with Lazarus's appraisal theory (Lazarus p.124) in that when a person has a strong personal involvement in a relationship the emotions experienced can show interdependency (e.g. love and hate). EOI and CC might 'flip over' with increasing frequency over time until the latter dominates. However, the sample of people who turned from High EOI to High CC was small (N=6), and the main previous study supporting the view that High EOI can change into High CC also had low numbers of people who actually did so (Stirling et al., 1993). Therefore the loss appraisal result requires replication with larger numbers. Also, the study does not report the proportion of people at baseline who were High CC with no High EOI, or who had both High CC and High EOI. So the whilst the results suggest that High CC can sometimes develop from High EOI, it does not show that this route to High CC is essential. The study of Patterson et al. is rare in that it focuses on first episode psychosis, it attempts to identify the content of carers' appraisals, and its design is strengthened by a follow-up.

4.6.5 Why the Components of EE Merit Separate Analysis

From the preceding summary of the relevant literature, it can be seen that a wide range of variables are associated with EE. Although EE and its three components do have correlates in common, this chapter has highlighted many of the differences that have been found. Concerning patients, the components differ in their relationship to relapse predictiveness, symptom type, social functioning and illegal drug use. Regarding carers, the components differ in their relationship to personality characteristics, attributional style, distress and appraisals of threat and loss. Within any given sample there is usually a very wide difference in the proportions of carers who display each component, suggesting that each has different determinants. Likewise, the fact that CC/H and EOI appear to differ both in their natural stability and in their resistance to intervention (e.g. Leff et al., 1982) also suggests they may have different determinants.

Many authors have argued that in order to understand the nature of EE, it is important to go beyond the traditional practice of overall High versus Low EE classification, and study the individual components too (e.g. Kavanagh, 1992; Chambless, Bryan, Aiken, Steketee & Hooley, 1999; Bentsen et al., 1996a). On the other hand, as discussed earlier, High CC and High EOI are commonly co-morbid. Greenley (1986) argued that whilst they are different responses, they are driven by a common need for social control of the patient. Patterson et al., (2000) also argue for a common core, but place emphasis on the appraisal of loss. In attempting to reconcile the 'different versus common core' viewpoints it could be argued that even though CC/H and EOI arise from a core common appraisal, what stimulates carers to adopt CC/H or EOI or both may depend on additional appraisal-related factors interacting with a core appraisal.

In order to understand the genesis of EE it is no longer acceptable to simply use the composite EE index, because it is now clear that it is likely to camouflage important differences in CC, H and EOI correlates. Differences in genesis between components may be important for treatment approaches (Birchwood, 2000). Given that many correlates have now been identified which might plausibly contribute to the development of High EE, what sort of model could organise them and explain why they are associated with EE?

4.6.6 A Carer Stress-Appraisal Model to Understand EE?

(i) Appraisal

In a comprehensive and authoritative review of all the major psychological models and theories of emotion Strongman (1996) concludes that Lazarus's appraisal theory (e.g. Lazarus & Folkman, 1984) is the most useful. Appraisals are evaluative judgements that mediate between the external environment and a person's emotional and behavioural responses to it. Primary appraisal involves assessing if a situation has goal relevance/irrelevance, goal congruence/incongruence, and the type of ego (i.e. goal) involvement (Lazarus & Folkman, 1991, p.133). Secondary appraisal concerns the likely effectiveness of the coping options the individual perceives are available to them in a situation. Since all encounters with the environment are continually changing and generating feedback about the psychological situation, primary and secondary appraisal are also constantly changing, which is why emotions are always in a state of flux. Lazarus and Folkman's theory posits a transactional relationship with external circumstances, so the situation a person is in is an important influence on the appraisal. However, appraisal is the process most proximal to emotional state (Lazarus & Folkman, 1991, p.138,), and it determines the quality, intensity and duration of emotional reactions (Perrez & Reichart, 1992, p. 27).

There is growing evidence that a carer appraisal model (e.g. Lazarus & Folkman, 1984) is useful in understanding how EE develops (e.g. Scazufca & Kuipers, 1996; 1998; 1999; Barrowclough & Parle, 1997; Boye et al., 1999; Patterson et al., 2000). A situation will be appraised as stressful, and therefore emotion-inducing, if it is deemed to be relevant to the person's goals but taxes or exceeds their coping resources. High EE carers may appraise their caring situation as more stressful than Low EE carers. High EE may be a form of coping, which is used to lower the perceived stressfulness of the caring situation (e.g. Greenley, 1986; Birchwood & Smith, 1987).

(ii) Evidence for A Stress-Appraisal Model of EE

A stress-appraisal model of EE appears to be able to find an underlying commonality among the diverse array of EE correlates that the literature has identified. To summarise: EE is associated with avoidant coping, which is used when a stressor is perceived to exceed perceived coping resources (Folkman & Lazarus, 1984). High EE carers also perceive

themselves to be coping less effectively (Smith et al., 1993). A stress-appraisal model explains why High EE is associated with higher burden (e.g. Scazufca & Kuipers, 1998) and higher distress (e.g. Shimodera et al., 1996; Boye et al., 1998; Barrowclough & Parle, 1997): because the High EE behaviours may be adopted to reduce the negative feelings that the perceived stressor causes. A stress-appraisal model involving burden and coping can help explain the instability of EE (e.g. McCreadie et al., 1993), because coping is a dynamic process (Folkman & Lazarus, 1985) and levels of burden and coping are known to interact (e.g. Szmukler et al., 1996). The likelihood of a stress-appraisal may also be increased by perceiving more disturbed behaviour (e.g. Bentsen et al., 1998c) and being in a nuclear rather than extended family (e.g. Leff et al., 1990). The model is also consistent with personality and attribution studies since being guilt-prone (Bentsen et al., 1998a) or seeing others' negative behaviour toward you as a conscious choice (e.g. Brewin et al., 1991; Harrison & Dadds, 1998) would increase stress. High EE carers seem to place more importance on interpersonal power than Low EE carers (Wuerker et al., 1996), which is also likely to lead to viewing aberrant behaviour as more stressful. High EE may be resorted to in order to regain mastery over the stressor in the situation (e.g. Greenley, 1986). High carer self-criticism (Docherty et al., 1998) might also undermine confidence and stress-coping mechanisms, increasing the stress of caring.

As discussed earlier, some objective patient illness factors (e.g. negative symptoms) and wider situational factors (e.g. culture) are also sometimes found to be associated with EE. A stress-appraisal model of EE does not discount the importance of these factors. The model is able to accommodate objective situational factors because within Lazarus and Folkman's (1984) framework people within a particular culture will often have a degree of shared appraisal about a situation. For example, this sort of sharing of primary appraisals in response to events was recently demonstrated for threat, loss, and challenge in a sample of depressed patients (Ferguson, Lawrence & Mathews, 2000). However, a carer stress-appraisal model would predict that whilst some objective factors might be associated with EE, appraisal would typically be the most powerful independent predictor. Indeed, differences in carer appraisal might explain why objective illness and situational factors are only usually inconsistently replicated.

(iii) Will a Stress-Appraisal Model Account for Early EE?

The data supporting a stress-appraisal model of EE is mainly based upon patients and carers who have been in their role for at least several years. It is not known if the model will be relevant to first episode users and carers, whose situation may differ in many ways from more chronic samples. A first episode sample will contain a wider spectrum of patient presentations (Yung, 1998) and it may be more representative of all carers. A first episode sample also overcomes the possible clouding effects of illness chronicity on EE correlates.

The one study which did examine carer appraisal in relation to EE at the first episode found support for its usefulness (Patterson et al., 2000). However, many of the appraisal variables associated with EE later in the course are completely untested with EE at the first episode. Such factors include burden, coping, perception of social functioning, distress and depression. Attempting to replicate these factors at the first episode might help with accounts not just of EE's maintenance, but also of its *genesis*. If a stress-appraisal model of EE is unable to account for early EE, for example because early EE is correlated with different factors, then this implies that EE may be influenced by different factors at different illness phases. For example, objective illness factors such as longer DUP might be stronger influences at the first episode (MacMillan et al., 1986; Patterson et al., 2000). Within a stress-appraisal model of EE, it is currently not clear if particular types of perceived stressor are particularly related to level of EE. For example, are particular areas of subjective burden, types of perceived social functioning or types of symptoms associated with EE more than others? It is also not clear if types of perceived stressor would, like later in the course, differentially associate with EE components. Such information could identify which factors to target to reduce EE in general or specific components.

The correlates of EE also have implications for stress-vulnerability frameworks of psychosis, since they might be able to specify circumstances in which the expression of psychotic symptoms are more likely. Clinically, knowledge of EE's early correlates may suggest what the locus of intervention should be, i.e. user, carer, situation or all three, to lower or even prevent it from developing.

4.6.7 A Next Step

The present study will test the usefulness of a carer stress-appraisal model of EE at the first episode of psychosis. In order to do this, variables which have been found to be associated with carer appraisal later in the course will be tested at the start of caring. As discussed in this chapter, subjective burden, perception of social functioning, avoidant coping, distress and depression are all related to carer appraisal and also to EE. Using Lazarus and Folkman's (1984) framework, carers who appraise their situation as more stressful are likely to show increased burden, perceive more social functioning problems, use more avoidant coping, and report increased distress and depression.

The present study does not attempt to answer all questions about the nature of EE. For example, as noted earlier, within Lazarus and Folkman's (1984) framework the wider objective environment is also important in the generation of emotion. The present study will test patient illness-related factors but does not seek to test the relative importance of wider circumstantial factors such as carer social isolation or carer stressful life events. The study also does not attempt to answer all questions about the relationship between carers' appraisal and EE. For example, whether the contents of carers' appraisal can be organised into higher order concepts such as 'threat' (Barrowclough & Parle, 1987) or 'loss' (Patterson et al., 2000).

To support an appraisal model not all carer appraisal variables need to be associated with EE. For example, a follow-up design might be required to reliably detect differences in distress. However, at least one carer appraisal variable obviously does need to be significantly associated with EE for the model to be supported. In addition, if carer appraisal is the strongest influence on EE, then variables associated with it should be stronger predictors of EE than other classes of variable. For example, carer appraisal should still predict EE when objective illness variables of the patient are statistically controlled.

The main aim of the present study is therefore to test the validity of a carer stress-appraisal model of EE. A secondary aim is to then test if illness-related factors are also associated with EE at the first episode, and if so, whether carers' appraisal will be a stronger independent predictor. Multivariate statistics will be used to identify the strongest predictors of EE. The issue of High EE co-morbidity will be addressed in two ways. First, in order to obtain more

clear-cut results a Low EE comparison group will be used with groups of carers High on each EE component. Secondly, a combination of post hoc descriptive and partial correlation calculations will be used in order to attempt to judge whether one or more components are responsible for any significant associations.

4.7 SUMMARY OF CHAPTER 4

This chapter has provided a discussion of the concept of EE. Despite over 40 years of research, the factors which underlie its development and maintenance are still poorly understood. High EE is highly prevalent throughout the course of psychosis and is a robust predictor of relapse, although with less power and reliability during the early phase. Although High EE is probably causally implicated in psychosis relapse, the mechanisms by which it does this are poorly understood and other factors might also contribute to its capacity to predict relapse. Theoretically, it has contributed to the development of stress-vulnerability frameworks of psychosis and frameworks of carer need. Clinically, EE research has led to family interventions which have been supported in many reviews, although there has been little such work at the first episode. EE levels are often unstable, suggesting that if factors can be correlated with change in EE, then determinants of the phenomenon may be isolated .

The latest phase of EE research involves serious attempts to understand its nature. However, the EE-correlate research literature has various methodological weaknesses. These include the use of small convenience samples, the reliance on instruments less valid than the CFI, and the study of either single correlates or more than one but with no statistical controls. A rarely mentioned issue is the influence High EE co-morbidity might have on correlates relationship with different EE components. This means that findings relating to EE components have less certainty than correlates of the overall High/Low classification.

A diverse array of EE correlates have been identified, including cultural, patient, carer and patient-carer-interactional factors. Since EE components are associated differentially with different correlates, it was argued that there are good grounds for analysing each component of EE (CC, H and EOI). It was argued, further, that a carer stress-appraisal model of EE is helpful in understanding how EE develops. Evidence for a stress-appraisal model of EE is tentative and in need of replication. Questions remain about its relevance to the start of caring,

and whether particular areas of perceived stress are more important than others in influencing both the level and component of EE.

The present study will therefore add to the understanding of EE by testing a stress-appraisal model at the first episode of psychosis. It is predicted that High EE carers will appraise their situation with greater burden, perceive more social problems in the patient, use more avoidant coping, and report more distress and depression than Low EE carers. A secondary prediction is that carer appraisal factors will be stronger predictors of EE than illness-related factors. Each component of EE will be analysed for its association with the potential correlates and multivariate statistics will be used to isolate the strongest predictors of each component. The study has theoretical implications for models of EE and clinical implications for lowering or preventing High EE.

Chapter 5:

The Method

5.1 INTRODUCTION

This chapter describes the method of the project's three studies (event-psychosis-onset study, event-delusional theme study, and EE-correlate study) in two sections. Section One sets out the main objectives of the project, the hypotheses, the design of each study, ethical issues, power analyses, identification procedure, sample sizes, inclusion/exclusion criteria and the instruments used. Section 2 defines the variables and statistics used for each of the three studies.

5.2 OBJECTIVES AND HYPOTHESES OF THE PROJECT

Objective i) To examine if stressful life events exert an influence on the onset of first episode psychosis.

Hypothesis i) Stressful life events will cluster in the final three months before onset compared to the previous nine months and the final three weeks before onset compared to the preceding nine weeks.

Null Hypothesis i) There will be no difference in the rate of events between the final three months before onset and the preceding nine months, nor between the final three weeks before onset and the preceding nine weeks.

Objective ii) To examine if type of stressful event predicts the development of type of delusional theme at first episode psychosis.

Hypothesis ii) Intrusive events will predict the development of a persecutory delusional theme.

Null Hypothesis ii) Intrusive events will not predict the presence of a persecutory delusional theme.

Objective iii) To examine if carer appraisal is both associated with EE and is a stronger predictor of EE than illness-related characteristics at the first episode of psychosis.

Hypothesis iii) Carers who are High EE (including carers who are High CC, H and High EOI) will have higher subjective burden, perceive more social functioning deficits, use more avoidant coping, have higher distress and higher depression than Low EE carers. Also, these carer appraisal variables will be stronger independent predictors of EE than the patient illness-related characteristics of diagnosis, symptom severity, symptom type, onset age and illness length. The carer appraisal hypothesis can be accepted if at least one of the appraisal variables is significantly associated with EE and is a stronger independent predictor of EE than the illness-related characteristics.

Null Hypothesis iii) Carer appraisal variables will not be associated with EE, nor will they be stronger predictors than patient illness-related variables.

5.3 PROJECT DESIGN

The stressful event-psychosis-onset study uses a within sample design, comparing the rate of events near to versus further away from onset. The stressful event–delusional theme study also uses a within sample design, but splits the sample into two groups: persecutory and not persecutory. The EE correlate study also employs a within sample design, and divides carers into Low EE versus High EE, High CC, H and High EOI.

5.4 ETHICAL ISSUES

The protocol of the study was submitted to the Maudsley and Bethlem NHS Trust before starting data collection. After ethical approval for the project was granted, all the consultants from the 26 wards and community teams were asked for permission to include patients under their care in the study. The study was explained to each ward or community team manager and the decision to approach patients was made after discussing the patient's current mental state with their key-worker. Patients who consented were assessed. If the patient consented, their carer was then asked about participating in the study. Patients and relatives were asked to sign a consent form (Appendices 4 and 10). Each patient who completed their assessment was paid £10. This was deemed a large enough incentive without inducing patients to participate against their better judgement.

5.5 SAMPLE SIZES

The software package nQuery was used to perform the power analysis calculations. It uses the following formula:

$$N = \frac{\delta_1^2 + \delta_2^2}{D^2} \times F$$

where N is the size of each group, δ_1^2 and δ_2^2 are the standard deviations for the 2 groups investigated, D is the difference between the means scores and F is a constant value which depends on the significance level and power required.

With reference to the life event-onset study, Day et al. (1987) found that events clustered within the final 3 weeks before onset compared to the previous nine at a p level of < 0.0001 using 50 patients from Camberwell who had first episode schizophrenia. The present study, which recruits in a similar geographical area, therefore aims to obtain a sample as near to 50 as possible, although recruiting slightly fewer participants is still likely to allow sufficient power to detect a difference if one exists. No power estimation was possible for the study linking delusional theme with event type as no previous studies were available to provide a plausible estimate of effect size. For the carer study, subjective burden is the principal EE explanatory variable being examined. Therefore, using data from Scazufca and Kuipers (1996) on EE and subjective burden, the power analysis indicates that there will be 78% power to detect a difference in means of -1.850 (the difference between a Group 1 Low EE mean of 2.19 and a group 2 High EE mean of 4.04), with a common standard deviation of 2.22 using a 2 group t-test with a 0.05 two-sided significance level, with a χ^2 test two sided, if 23 participants in each group are used. This level of power is very close to the generally accepted recommendation of 80% (e.g. Cohen, 1977). Given the fact that this is an exploratory rather than confirmatory study, 46 carers would appear to be an acceptable number in terms of the power analysis for the EE study. However, caution is necessary because unlike the present study, the project of Scazufca and Kuipers (1996) included only people with schizophrenia and was not a first episode study.

5.6 IDENTIFICATION PROCEDURE

There were 26 referral 'units' covering The Maudsley, Bethlem, Mayday and Warlingham hospitals and all their associated community mental health teams. All community teams included in the study were contacted at least once a week and all wards were contacted three times per week. The Trust Bed Manager was contacted on a daily basis. The referral locations are listed in Appendix 19. Approximately three months after the author started identification and data collection, the identification workload was divided between the author and three other IOP researchers (Kathy Greenwood, Ph.D. student in Psychology, Karena Meehan and Paul Fearon, both Senior Registrars in Psychiatry).

5.7 PATIENT INCLUSION / EXCLUSION CRITERIA

i) Patient Inclusion Criteria

ICD-10 diagnosis of psychosis as produced by the CATEGO program

Age 16 - 65

Informed Consent for interview

English speaking

For the Life Event studies:

Onset within 12 months before interview

Dateable onset within 1 week. Onset defined as the first emergence of delusions, hallucinations or formal thought disorder as defined by SCAN criteria

The presence of persecutory, referential, grandiose or depressive psychotic themes in delusions or auditory hallucinations¹

ii) Patient Exclusion Criteria

Gross organic pathology

Moderate or severe learning disability

¹ The voice criteria was used for a sub-study which is not included in this thesis.

iii) Carer Inclusion Criteria

Living with or in close contact (at least once per week) with the patient for at least three months before interview.

Key Carer (i.e. the person with highest face-to-face contact)

English speaking

Informed consent for interview

5.8 INSTRUMENTS

5.8.1 Patient Assessment Instruments

i) Patient Socio-demographic and Illness-related Characteristic Form (Appendix 5)

A standard form was used to collect information on patient socio-demographic and illness-related characteristics.

Patient Socio-Demographic Characteristics:

The data recorded included: age, sex, ethnicity, employment, marital status, cohabitation status and number of own children at home.

Patient Illness-Related Characteristics:

The data included illness length at interview and age of onset.

ii) Psychopathological Status: SCAN 1.1

SCAN 1.1 (WHO, 1992) is a set of instruments for assessing, measuring and classifying the psychopathology and behaviour associated with the major psychiatric disorders. It has four components: the tenth edition of the Present State Examination, a Glossary of Differential Definitions, the Item Group Checklist and the Clinical History Schedule. PSE10 itself has two parts. Part one covers principally non-psychotic disorders and part two covers psychotic conditions. The computer program CATEGO5 is used to process data entered from the SCAN schedules. The program produces diagnoses, a total score for psychopathology, scores for neurotic, depressive, manic and psychotic symptom dimensions and syndrome scores for each group of symptoms.

The following sections were not used: Use of Alcohol (Section 11), Use of Psychoactive Drugs (Section 12), Motor and Behavioural items (Section 21), (Additional) Affect (Section 22), and Social Impairment (Section 24). A separate form recorded basic information about recent intake of alcohol and drugs. Also, none of the 'Optional Checklists' were used. The omitted sections do not contribute to the psychosis diagnosis.

If the patient was currently psychotic then the period chosen for assessment was usually the Present State (PS) (last 28 days). If the patient was not currently psychotic then the Representative Episode (RE) was used (28 days of the illness, usually the most severe, which included the most representative clinical picture of the illness). If a patient had a previous episode of a psychiatric illness (e.g. depression) then RE was used as well as the PS (this is useful for diagnoses that depend on a prior episode such as bi-polar disorder). For patients unable or unwilling to be assessed adequately, the Item group Checklist can be used with CATEGO5 to make a diagnosis based on all available evidence. (This was in fact used only once in the present sample).

Most questions in the PSE-10 are rated as 0-Absent, 1-present but of such a minor degree that it is not appropriate for use in classification, 2-moderate severity/present for part of the period under review, 3-severe for most of the period under review

Symptoms were rated based on all available sources, primarily interview but - if credible - case note evidence, key worker information, and carer information also informed the ratings. Patients' responses were input directly into the CATEGO5 computer program by interviewing with a laptop computer. The author was trained in the use of the SCAN by Professor Paul Bebbington who gave advice on unclear patient responses.

Identification of Psychosis Themes

The key theme of interest is persecutory. However, the study also included patients with three themes other than persecutory so that a comparison group could be collected. The themes chosen were ones which were thought common enough to enable a sufficient number of patients to be found. Therefore the other three themes included were reference, grandiose and depressive. An additional benefit of including a reasonable number of other themes is that they

can be used for post-hoc theme specificity testing i.e. if intrusive events are associated with a persecutory theme, it will then be possible to test if intrusive events are also associated with the other themes or just a persecutory theme.

The definition of a persecutory delusion in SCAN 1.1 is this: “Respondents believe that someone, or some organisation, or some force or power, is trying to harm them in some way; to damage their reputation, to cause them bodily injury, to drive them mad or to bring about their death”. A persecutory delusion was rated as present if a score of at least 2 on the 1-3 scale was given for SCAN Item Group 30 Delusions of Persecution (19.12, delusions of persecution; or 19.13, delusions of conspiracy).

The definition of a referential delusional theme in SCAN 1.1 is that it is characterised by a misattribution of the significance of people, objects or events that are perceived normally. A reference theme was rated as present if a score of at least 2 on any of the SCAN Item Group 29 Reference Delusions items (19.3, delusions of being spied upon; 19.4, delusions of reference; 19.5, delusional interpretation; 19.6, quotation of ideas; 19.7, delusional misidentification; and 19.8, familiar people impersonated).

The SCAN does not contain a definition of depressive delusional theme. However, a depressive delusional theme was rated in the present study if any of the following Item Group 13, Depressive delusions, items scored 2 or more (19.10, depressive reference delusions; 19.30, delusions of guilt: depressive; 19.31, delusions of catastrophe/depressive; or 19.32, hypochondriacal delusions/depressive).

The SCAN does not contain a definition of grandiose delusional theme either. However, a grandiose delusional theme was considered present if a rating of at least 2 on the scale of 1-3 was given for any of the following items in Item Group 18: 19.11, reference delusions expansive; 19.34, grandiose ability; 19.35, grandiose identity.

SCAN Reliability:

Reliability (inter-rater and test-re-test) of the PSE instrument approach per se is well established (Wing, 1990). Field trials of SCAN were undertaken by WHO in 20 centres in 14

countries and the results indicate that reliability (between interviewer and observer and also between two interviewers over time) is fully up to the high standards of the earlier editions of the instrument (SCAN Glossary p.6, WHO 1992; Wing, 1990). Where patient delusional themes were unclear they were checked with Professor Bebbington.

SCAN Validity:

Serious doubts about the validity of the psychotic diagnoses upon which the SCAN approach is based have been raised (e.g. Bentall, 1990; Boyle, 1990; Castle et al., 1998). However, this study requires only a diagnosis of functional psychosis per se, not any particular type of psychosis, and the instrument has demonstrated discriminant validity in that its guidelines can enable it to detect whether or not psychosis is present (Wing, 1990). It has excellent face validity. Convergent and concurrent validity may not be a relevant issue because the ICD-10 system upon which it is based is itself accepted as the “gold standard” in the U.K.

iii) Life Event and Difficulties: The Life Event and Difficulties 2 (LEDS2, Appendix 7)

The LEDS2 (Brown & Harris et al., 1989) is a semi-structured interview that assesses stressful life events and difficulties, based on a system of the likely meaning of the events to the subject. The period covered in the present study was the 12 months before illness onset. Biographical and socio-demographic information was taken from the respondent before the interview.

Basic LEDS Scales: Event Independence, Threat and the other Stress Dimensions

The LEDS2 has a variable number of scales depending on which dimensions are needed to rate events. Data from 34 event scales were collected in the present study, but the two most important are the Independence and Threat scales.

a) Independence

Independence refers to the degree to which respondents could conceivably have been responsible for the occurrence of the event, if the hypothetical disorder was present. It is rated on an 11 point scale with points 1-4 being ‘Independent’ events, 5 being a mixture of the ‘independence and dependence’, and 6-11 being ‘possibly independent’. Although every event

was rated on this scale, for the purpose of analysis in the present study, events were categorised into a) 'independent' or b) 'independent or possibly independent'.

b) Threat

Threat is rated by the researcher according to the all round contextual unpleasantness of the event. The Threat rating is assigned according to how an average person would find the event, given the respondent's biographical circumstances. It is rated along a 4-point scale of 1-Marked Threat, 2-Moderate Threat, 3-Some Threat and 4-Little/No Threat. The Threat is rated both for the short-term Threat (i.e. within the first 14 days), and the long-term threat (i.e. Threat level after 14 days). For the purpose of analysis in the present study, as with other event studies, only the long-term rating was used. The Threat dimension was the key independent variable in the stressful event-psychosis first onset study.

Other LEDS Scales used in the Present Study:

Since the initial Threat scale was devised, a number of more specific scales have been constructed. Intrusiveness is included because of the hypothesis concerning event type and delusional theme. In addition, scales were included for Loss, Danger, Humiliation, and for another scale called Self-Esteem, which was developed as an extension of the Humiliation scale for the purpose of the present project. Events are rated on Threat, and then, if Threat is at least moderate, an event is rated on Loss and Danger. After this, Humiliation can be rated. Separate from this scheme, all events were rated on Intrusiveness and Self-esteem irrespective of the Threat level. Below is a description of each of the scales. The other scales are included in the present study for two reasons. First, they can be used for post hoc event-specificity testing i.e. if intrusive events are associated with persecutory delusions, it will be possible to test if all events or just intrusive events are associated. Secondly, there is little data concerning what type of events occur before the first episode, so the study will be able to contribute new descriptive information about this.

c) Loss

Loss is only rated if the event is rated at least 2-Moderate Threat. It is only assessed on a long-term contextual basis. It is rated along a 4 point scale of 1-Marked Loss, 2-Moderate Loss 3-

Some Loss and 4-Little/None. To facilitate recognition of Loss in an event, scale guidelines identify four types of External loss and two types of Internal loss for the researcher to identify.

The four types of External Loss are defined as: Loss of material possessions/money, loss of person, loss of community respect or loss of employment. Internal Loss relates to loss of a 'cherished idea' about the self or others. Such loss may involve a sense of failure or doubt about a central expectation/assumption. Loss of cherished idea about someone else can be latent, which involves violation of taken-for-granted assumptions, which will tend only to be brought to notice by the Loss event itself; or Active where in contrast to Latent, characteristics, aspirations or expectations are to some degree uncertain at the time of the occurrence of the event and can be expected to be capable of producing considerable emotion. These categories are not mutually exclusive. Loss is rated 1-Marked 2-Moderate 3-Some 4-little/none.

d) Danger

Danger events are those that suggest the possibility of a future loss. Danger events can be classified along the lines of the Loss categories. Two factors are taken into account when rating Danger: the unpleasantness of the event and the likelihood of it actually happening. Danger was included in the present study for the sake of completeness. Danger is only rated if the event is rated at least 2-Moderate on long-term contextual Threat. It is rated along a 4 point scale of 1-Marked Danger, 2-Moderate Danger 3-Some Danger and 4-Little/No Danger.

e) Humiliation

Humiliating events involve the person being socially de-valued in relation to self or others. Usually only events involving core ties are included, but if an event is particularly shameful other people can be included. Only events rated at least lower 2-Moderate Threat on long-term contextual Threat can be included. Unlike the other scales, Humiliation is rated just as present/absent. The three categories of Humiliation rated are 1) Separation: this refers to separations from partners/lovers where it appears permanent and the other person took the initiative in breaking off the relationship, or the respondent broke the relationship after the discovery of infidelity or violence so that the respondent was 'forced' to act. Some element of rejection or failure must be involved 2) Others' Delinquency: this refers to events of a

delinquent nature carried out by someone else which reflects on the respondent in a socially devaluing way. The other person is usually a very close tie. A special case must be made for the inclusion of events by non-close ties 3) Put Down: this should involve what is likely to be a central aspect of self-identity. Such events typically refer to acts against the subject by very close others, such as involving physical violence, verbal attacks or public reprimands by figures of authority. Other people can be included e.g. all rapes are included. Most humiliating events involve the behaviour of others toward the subject but a second class of Humiliation involves a Self-Originating Putdown. Most such events will involve personal failure e.g. infertility.

f) Intrusiveness

Intrusive events involve interference and attempted control of the subject by outsiders or people where there is no evidence of closeness. A special case must be made for including people who are not outsiders to the person. Usually but not always, Intrusive events involve intent to harm and will often be committed by a figure of authority. The scale is rated on 1-Marked 2-Moderate 3-Some and 4-Little/None. It is rated only contextually and severity can be rated because of either short or long-term effects of the event.

g) Self-Esteem

Self-Esteem is an evaluative component of the self-concept (Brewin, 1988). The scale was created for the present study from the work of Bentall and colleagues (as described in Chapter 3). Self-Esteem reducing events are those that either deprive the Self of an important source of worth or involve a situation that actively devalues self-worth. Such events would be expected to reduce the overall value individuals place on themselves. There are two broad classes of such events. These are first, events that respondents themselves cause which lower self-esteem. Such events will often involve personal failure in areas such as education, work, reproduction or relationships. The importance of the failure, and how directly personal shortcomings are implicated, will influence the rating.

A second class of events that lower self-esteem are those caused by other people. Such events will often also meet the criteria of Brown et al. (1995) for Humiliation. However whilst what is humiliating will always be self-esteem reducing, what is self-esteem lowering will not always be humiliating. Thus Humiliation is just one way of lowering self-esteem. It is also true that a

given event that is both humiliating and self-esteem reducing will not necessarily receive the same severity rating for each category. For example, it is possible that an event, which is only mildly humiliating, will be severely self-esteem reducing because its implications will be mainly private to the patient and not public knowledge. Similarly, it is possible that an event which is highly humiliating will not necessarily be expected to reduce self-esteem to the same extent because the patient knows the public implication is misleading.

Events that involve devaluing a core role or aspect of self-identity are also likely to lower self-esteem. For example, employment and personal relationships are factors that ordinarily would be expected to affect self-esteem. Examples of events which would be expected to reduce an individual's self-esteem include a verbal attack, failing an exam, facial disfigurement, being divorced and being sacked.

Validity and Reliability of the LEDS:

LEDS Validity:

The LEDS has considerable face validity. It also has some predictive validity in that in some studies events have been found to cluster just before psychotic relapse (e.g. Vaughn & Leff, 1980), including at first onset (Day et al., 1987). A different design, comparing normal controls to people with psychosis, has shown that this clustering is in excess in the psychosis group, and that normal controls do not show clustering just before interview (e.g. Bebbington et al., 1993; Brown & Birley 1968).

In the Brown and Birley (1968) schizophrenia study, comparing relatives' and patients' reports as a measure of accuracy or concurrent validity, there was an 81% agreement on whether a particular event occurred in the 3-month period before onset (Brown et al., 1973). Similar results were reported over a 12 month period in a study of depressed patients, in which there was a 79% agreement between relative and patient on whether an event had occurred, increasing to 92% for events of at least moderate severity (Brown et al., 1973). With reference to the accuracy of individual event dating, Brown and Harris (1982) report that in their depression study there was only a difference of 2.4 weeks between patients' and relatives'

accounts, with 79% of pairs differing by no more than 3 weeks and 90% by no more than 5 weeks.

With reference to the validity of using the LEDS to ask people with psychosis about events that occurred up to 12 months before onset, the present study is the first to do this. However, one other methodologically adequate study used a checklist of events to assess the 12 months before onset (Jacobs & Myers, 1976). They found more events than in a normal control group for the entire 12-month period, supporting the validity of the LEDS with psychosis patients over a longer recall period. In depression research the LEDS has commonly been used over a 12-month period before onset, and it should be noted that the actual time period would extend beyond this because there is always a gap between onset and interview. However this is not conclusive evidence about the validity of the LEDS with psychosis patients over a longer period. Although the LEDS has not been used before over such a long period, Bebbington et al. (1993) did use a six month period, with onset dateable within the last year, so onset could have been as far back as eighteen months before interview. They were able to demonstrate an excess of events compared to normal controls even several months before onset.

The validity of the LEDS approach over time has in fact been checked in terms of the level of fall-off in reporting of events over time. By applying the reasoning that events occur with a random distribution over time, if less events are found further back in time, this is evidence for inaccuracy or weaker validity. Studies indicate no significant fall off of events of at least moderate severity over a period of 1 year before onset in the general population (Brown & Birley, 1968; Brown & Harris, 1989). However there does appear to be a significant fall-off of events of at least moderate severity, as for example in the depression studies in South London and the Outer Hebrides (Brown & Harris, 1989). Brown and Harris (1989) report that the fall-off rates for events over a 10 year retrospective period in a group of male civil servants was only 2.9% per year, and for a general population sample only 5.8% per year. Wittchen, Essau, Hecht, Teder & Pfister (1989) used raters trained in the use of a life event list to assess life events in a mixed group of psychotic and neurotic patients. The fall off over 7 years was only 0.36% per month overall and even less for events of at least moderate severity. A related issue here is the 'mood-congruence hypothesis', which suggests that people recall events according to their mood at interview, so for example, depressed people would recall more negative events

than their non-depressed counterparts. Wittchen et al., were able to demonstrate similar and satisfactory fall-off results for discharged patients with depression and schizophrenia, whether or not they still had significant symptoms.

Taken together, there is strong evidence for the validity of using the LEDS in the present study.

LEDS Reliability:

With reference to the reliability of the LEDS approach, the level of agreement on long-term contextual threat between the original raters in the Brown and Birley (1968) schizophrenia study was $r=0.75$ (reported in Brown et al., 1973). Disagreement between raters on the various scales was uncommon (Brown & Birley, 1968). Inter-rater reliability over the six months before the onset of psychosis was high in the study of Bebbington et al. (1993), with 81% agreement on the level of long-term contextual threat. Currently, there are no published studies of inter-rater reliability using the LEDS scales for a period of 12 months before the onset of psychosis, but high inter-rater reliability has been found using a checklist. For example, Al Khani et al. (1986) achieved 98% agreement on whether a typed narrative account was an event or not, and 94% agreement on the degree of independence on a three point scale. High inter-rater reliability on most LEDS scales has commonly been found over a 12-month period with depressed and normal control patients (Brown & Harris, 1989). The reliability of measures of LEDS2 specific dimensions over a 12-month period has been found to be high both with normal controls and depressed patients, with at least 0.90 agreement between raters on most original scales (LEDS2 manual 1989, p.31, statistic used not reported). The inter-rater reliability of the newer Loss and Danger scales was .83 to .92 for Loss between different raters, and for Danger it ranged between 0.70 to 0.87 (weighted Kappa, Brown & Harris, 1989, p.104). The Humiliation scale used in the present study is part of a larger twelve-category scale. The inter-rater reliability for the 12-point scale was 0.90 (Kappa, Brown et al., 1995).

The author was trained in the use of the LEDS2 by Tirril Harris and submitted 3 audio-tapes of patient interviews that were judged reliable by her. The Self-Esteem scale created for the purposes of the present study was checked by selecting 20 events and presenting them to Tirril Harris who was blind to the author's ratings.

Taken together, the evidence is that the LEDS is reliable if formal training is taken and the panel method is adhered to.

5.8.2 Carer Assessment Instruments

(i) Carer Socio-Demographic Characteristics Form (Appendix 11)

A standard form was used to collect information on socio-demographic characteristics. The data recorded included age, sex, ethnic origin, household composition, employment status, occupation, marital status, cohabitation status, number of own children at home, relationship to the patient, interview location, whether patient in hospital at time of the interview, whether carer lived with the patient, whether carer lived with the patient at illness onset, number of hours in face-to-face contact and whether the carer had had previous psychiatric caring experience.

Face-to-face contact was based on the typical amount in the period before admission. In a small number of cases, carers were not in contact with the patients just before admission, but had been in close contact with them for at least 3 months by visiting the ward regularly and keeping in touch with developments, or were now caring for them in the community, thereby meeting the three month criteria.

ii) The Camberwell Family Interview (CFI) (Appendix 12)

The Camberwell Family Interview (CFI) (Vaughn & Leff, 1976a) is a semi-structured interview that asks carers about the start of the patients' problems, focusing on the previous three months, covering how patients spend their time and how their behaviour has changed. Moore (1991) re-organised the questionnaire format without changing the content. A different format has been used in several published studies (e.g. Moore et al., 1992; Ball et al., 1992; Scazufca & Kuipers, 1996; 1998; MacCarthy, Kuipers, Hurry, Harper & Lesage, 1989). The present study used the Moore (1991) CFI format. All interviews were tape-recorded. A relative was considered High EE if they made six or more critical comments, revealed any Hostility or was rated three or more on Emotional Over Involvement.

CFI Reliability:

The CFI is reliable in that high inter-rater reliability can be and usually is obtained through training. Rutter and Brown (1966) present evidence of reliability and validity for the original CFI. As noted in Chapter 3, Bentsen et al. (1996a) examined the issue in a group of seven raters who were more representative of the population of typical raters. They found that reliability was usually lower than expected, with Kappas of 0.51 for EOI, 0.67 for CC and 0.61 for Hostility. The current author was trained in EE assessment by Dr. Christine Vaughn, reaching the acceptable reliability levels of: Critical Comments = 0.92; Hostility = 0.80; EOI = 1.00; Overall EE 0.82 (by the Phi co-efficient), Warmth = 0.86 (Spearman's rho) and Positive Remarks = 0.81 (Pearson product moment).

CFI Validity:

As discussed in Chapter 4, EE and thus the CFI, has a well-established, robust and powerful relapse predictive validity. CFI scores also interact with medication and face-to-face contact to predict relapse in a way that would be expected if the CFI scores were valid measures of psychosocial stress. The direct interaction studies indicate that CFI scores are measuring something that does actually happen outside the interview. The physiological studies suggest that the CFI scores are also associated in a meaningful way with biological phenomena. The link between affective style and CFI scores also supports the construct validity of the latter. Recently, further support for validity was found in a study which linked relatives' empathy to relapse (Giron & Beneyto, 1998). Finally, two factor-analytic studies support the factorial validity of the CFI scores (Parker, Hayward & Johnstone, 1989; Chambless et al., 1999). Evidence for the validity of the CFI is therefore considerable.

iii) The Experience of Caregiving Inventory (ECI) (Appendix 13)

The Experience of Caregiving Inventory (ECI) (Szmukler et al., 1996) is a 66 item instrument assessing the subjective experience of caregiving in eight areas covering difficult behaviours, negative symptoms, stigma, problems with services, effects on the family, need to back up, dependency and loss, and two areas of positive experiences of caring, covering positive personal experiences and good aspects of the relationship. The instrument measures how often carers have thought about each issue over the last month before interview, on a scale of

0=never, 1=rarely, 2=sometimes, 3=often, 4=nearly always. Carers were asked each question verbally and their answers were noted on the ECI response form.

ECI Reliability:

The scale was derived by asking carers (N=625) to state problems they had experienced. A principal components analysis reduced items identified to 66 items and 10 subscales. Each item loads to a satisfactory degree on its sub-scale, yielding a satisfactory cronbach alpha-coefficient, supporting its internal consistency. Also, the negative scales are inter-correlated around 0.5 with each other, as are the positive scales with each other, again supporting internal consistency/reliability of the instrument as a whole.

ECI Validity: The instrument has excellent face validity, and there is good data supporting its construct validity, since it predicts GHQ and negative affect scores when entered with coping style into a stress-coping statistical model.

Though the ECI instrument includes two positive scales in order to go beyond the notion of caregiver burden, the eight negative experiences sub-scales were, in this study, summed to produce a total negative experience or 'subjective Burden' score. Szmukler et al. (1996) have used a total negative and positive score in the validation of the instrument, for example they found that the sum of the ECI negative scales predicted GHQ variance with similar power to entering each scale individually.

iv) The Cope (Appendix 14)

The Cope (Carver et al., 1989; Carver et al., 1994) is a multidimensional inventory to assess the different ways people respond to stress in terms of different coping styles. The instrument was used to measure how often carers used each of the coping styles when they experienced stress and problems related to the patient, on a scale of 1= never, 2=rarely, 3=sometimes, 4=a lot. The total score for each scale is found by adding the items together. In the present study, if the carer had been involved in caring for months or years, the frequency rating was based on the typical coping behaviour over the most recent period. The Cope was constructed from a theoretical rather than empirical approach, using two main theoretical models as guidelines: the Lazarus model of stress, and a model of behavioural self-regulation that has guided Carver's

own as well as ideas from existing coping measures. Using this approach, Carver et al. (1989) created coping style scales, and gave them to 978 normal participants. The scores were subjected to a principal components analysis, from which 14 scales were derived.

In the present study the scales of behavioural disengagement (items 10 and 15), mental disengagement (items 1 and 13), alcohol-drug use (items 2 and 12) and denial (items 9 and 27) were used and summed to derive a more general 'avoidant' coping scale. This allows comparison with studies that found a link between avoidant coping and EE (e.g. Scazufca & Kuipers, 1996). This is a style characterised by temporarily escaping (psychologically or behaviourally) from the stressor, rather than trying to eliminate the source of the stress itself or altering one's attitude toward the stressor. It should be noted that the 'avoidant' composite scale used in the present study does not contain exactly the same sub-scales as that which Carver labels the 'less adaptive coping' category. The avoidant scale leaves out 'venting' but includes 'denial', which Carver includes in the emotion-focused category. However, the reliability and validity data supporting Carver's instrument relate primarily to the individual scales rather than how they can be grouped into broader categories such as 'problem-focused', emotion-focused, so they should still apply to the sub-scales which comprise the 'avoidant' scale in the present study.

Cope Reliability:

The Cope scales high alpha and test-retest results indicate good reliability (Carver et al., 1989; Carver et al., 1994).

Cope Validity:

The validity of the Cope has been approached by correlating relevant scales with personality measures of optimism versus pessimism, stressor controllability, self-esteem, locus of control, hardiness (commitment, control and challenge), type A behaviour, trait anxiety, monitoring (seeking out information about one's situation and its potential impact) v blunting (dealing with a stressor by distraction), and a social desirability scale.

Convergent validity was supported by the fact that coping styles that are widely regarded to be functional were linked to personality qualities that are widely regarded as beneficial and coping

tendencies hypothesised to be less functional were inversely associated with these personality qualities.

Discriminant validity was supported in three ways: a) Although the personality variables tended to correlate with coping strategies in accordance with theoretical predictions, the correlations were not overly strong, implying that the personality variables and the coping styles were not identical. b) The Cope scales were not strongly correlated with the social desirability scale. c) The Cope scales were unrelated to the blunting/monitoring scales they were compared to, suggesting the two measures are complementary, and do not assess similar qualities of coping.

Due to the length of the instrument and overall assessment load on respondents Carver et al. have shortened the Cope to two to three questions per coping style instead of four, based on the highest factor loading of each item and the appropriateness of the item to the group under study. The present study also used this type of approach for the same reason, using two questions per scale, as suggested by Carver in unpublished notes about the instrument (Carver, personal communication, 1997). Carver et al. (1994) indicate that internal reliabilities for the shortened versions of all the scales, in a three-question per scale shortened version, were adequate (alphas ranged from .65 to .90). The high factor loadings of each question on its subscale, the demonstrated reliability of a three-item-per-scale approach and the recommendation by Carver et al. (1994) all support the use of the two-item per scale approach in the present study.

v) The Social Functioning Scale (Appendix 15)

The Social Functioning Scale (SFS) (Birchwood, Smith, Cochrane, Wetton, & Copestake, 1990) measures those areas of functioning that are crucial for the community maintenance of individuals with schizophrenia. The format used is provided by Barrowclough and Tarrier (1992). Carers were asked about the patients' typical recent social functioning and some questions specifically request information about the last three months. Their answers were recorded on the questionnaire. Using the SFS at first episode sometimes required some adaptation of the rating. This is because the instrument was developed to assess patients with more stable and chronic illness histories who were discharged into the community, whereas the actual total illness duration of some first episode patients was less than three months. The

period asked about was either the three months before admission or (where the patient was not admitted), the three months before interview. All interviews were conducted either while the patient was in hospital (45%) or soon after discharge (55%). Many questions require a frequency judgement over the last three months. Where social functioning had deteriorated within the last 3 months, the recent period of deterioration was focused upon, so that the non-ill period did not influence the scores. However, in cases where onset and admission was rapid (i.e. less than two weeks) the questions requiring frequency ratings were not made solely on those few days of illness as it was felt this period was too short to provide a typical representation of the carers' perceptions of the patients' social functioning before admission / interview. The frequency ratings in very acute cases therefore reflected the 'well' period too.

Seven areas are covered by the SFS. Employment: engagement in a productive employment or structured programme of daily activity. Social Withdrawal: time spent alone, initiation of conversations, social avoidance. Pro-social activities: engagement in a range of common social activities (e.g. going to the pub). Recreation: engagement in a common range of hobbies, interests or pastimes (e.g. gardening swimming). Interpersonal Functioning (e.g. quality of communication and numbers of friends) Perceived Independence Competence (ability to perform skills necessary for daily living), Perceived Independence Performance i.e. how often they actually did things (such as washed, shopped, cleaned, etc.). A Total score is calculated by adding all the sub-scales.

SFS Reliability:

Birchwood et al. (1990) present four types of reliability data on the instrument. First, the alpha co-efficient measures the percentage of the test score variance attributable to 'true' variance in the characteristic being measured. All scale alpha co-efficients are high. Secondly, inter-rater and rater-self-report reliabilities indicate that the SFS is measuring characteristics about which the individual and relatives concur, since no differences were observed in these comparisons. Thirdly, it is reported that part of the variance of individual items is determined by the characteristic being measured, because the item-total correlations for the scales show a high level of internal consistency in the SFS scales.

SFS Validity:

Birchwood et al. (1990) present construct and discriminant validity data on the SFS: construct validity was established by a factor analysis using the alpha method. One factor was extracted which accounted for 57% of the variance, and the factor structure together with the high correlations between the SFS items and the factor scores suggests that it is valid to obtain a full score by summing the sub-scales. Discriminant validity was established by comparing the scores of people with schizophrenia with a community sample and also with those of the siblings of people with schizophrenia. The SFS achieved a high degree of discrimination in both cases.

vi) The Beck Depression Inventory (BDI)

The Beck Depression Inventory (BDI) (Beck & Steer 1987) is a 21 item self-report instrument designed to assess the severity of depression. The 1993 instruction manual recommends the following scoring classifications: 0-9 no depression; 10-16 mild depression; 17-29 moderate depression; 30-63 severe depression. The review by Richter et al. (1998) of the BDI's psychometric properties concluded that the instrument has good discriminant validity (when comparing depressives with non-depressives), convergent and content validity and high internal (alpha) reliability.

vii) General Health Questionnaire

The 28-item version of the General Health Questionnaire (GHQ) (Goldberg & Williams, 1988) is a self-report instrument that aims to detect psychiatric disorders amongst a non-psychiatric population. In the current study it was scored 0,1,2,3, and was also used 0011 with the definition of a case of 5 or more. It has a total score and four sub-scales of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. Its reliability (alpha) and validity (content, construct and discriminant) appear acceptable (Goldberg & Hillier, 1979; Goldberg & Williams, 1988).

5.9 VARIABLES AND STATISTICS USED IN THE ANALYSIS

5.9.1 Variables and Statistics used in the Stressful Event – Onset Analysis

The dependent variable was the period before psychosis onset and the independent variable was the rate of events. The final three weeks were compared with the preceding nine weeks, and the final three months were compared with the preceding nine months. The rate of events was measured in terms of the number of events and the proportion of people who had at least one event. The Wilcoxon test for two related samples was used to compare the periods closer to onset with the periods further away.

5.9.2 Variables and Statistics used in the Stressful Event - Theme Analysis

The dependent variable was the presence of a persecutory delusional theme. For comparison purposes, referential, grandiose and depressive themes were also included. Persecutory theme was tested for its hypothesised association with intrusive events, in two ways. First, the number of events in each group (persecutory theme present versus absent). Secondly, the proportion of people who experienced at least one event in each group (persecutory theme present versus absent). Both types of statistic were repeated for the full twelve months, the final twelve weeks and the final three weeks. The t-test and Mann Whitney U tests were used.

5.9.3 Variables used in the EE Correlate Study

The main outcome variable was Expressed Emotion and it was categorised in five ways: Low EE, High EE, High CC, H and High EOI. Its explanatory variables were subjective burden, avoidant coping, perceived social functioning, depression, distress; and the illness-related characteristics of the patient were diagnosis, symptom severity, symptom type, illness length, and onset age.

i) Carer variables:

Expressed Emotion: divided into Low EE (<6 CC and < 1H and <3 EOI), High EE (≥ 6 CC or >0 Hostility or ≥ 3 EOI), High CC (≥ 6), H (>0) and High EOI (≥ 3).

Carer Socio-Demographic characteristics:

These were described in section 5.8.2 (i).

Subjective Burden:

All the ECI scales were used, as described in section 5.8.2 (iii)

Coping:

Avoidant coping as described in section 5.8.2 (iv)

Perceived Social Functioning:

All the scales were used, as described in section 5.8.2 (v)

Depression:

The BDI score was used as a continuous variable, as described in section 5.8.2 (vi)

GHQ:

The GHQ score was used as a continuous variable.

ii) Patient Variables Used In the Carer Analysis**Socio-demographic characteristics**

These were used as listed in section 5.8.1 (i). Ethnic origin was used as black (African, Caribbean, Indian, Pakistani) / White.

Patient Illness-related characteristics

These were used as listed in section 5.8.1(i). The SCAN scores used were the neurotic total, depressive total, manic total, psychotic total, total symptomatology, 70 symptom groups, index of definition and schizophrenia/schizo-affective yes/no.

Statistics Used in the Carer Study

Univariate analyses was used to investigate possible links between dependent and independent variables. Multivariate analyses were used to control for the effect of various variables being linked to a dependent variable and so to isolate variables which were associated to the dependent variable simply because they were linked to another independent variable. The relevant statistics (e.g. mean, actual p-values, etc.) were quoted with each result. In order to

identify the EE component most likely to be responsible for any correlates found to be statistically significant, simple descriptive calculations of EE sub-groups and partial correlations of the CC and EOI as continuous components were used.

Univariate Analysis

a) Two Categorical Variables:

Contingency tables were used to compare proportions for categorical variables. Although there is a single general approach to the analysis of all frequency tables, in practise the particular method of analysis varies according to the number of categories, whether the categories are ordered or not, the number of independent groups of participants and the nature of the question being asked (Altman, 1991, p. 241-2). Test co-efficients, degrees of freedom and p-values were reported

The Chi square statistic was used to compare proportions of unordered categorical variables.

The Mantel-Hanszel test was used to test for linear association between one ordered categorical variable and one unordered categorical variable.

Fishers exact test was usually used where one of the cell expected frequencies was less than 5.

Three Continuous Variables where one needs controlling

Partial correlations were used.

One Continuous Variable and One Categorical Variable:

The independent t-test was used when two independent groups of observations were compared. The assumptions of the test were checked before each use of it, namely that each of the observations were from populations with a normal distribution and that the variances were similar. Box plots tested the first assumption and where extreme values were found (i.e. >2 standard deviations from the mean) the test was repeated without the extreme value. If the distributions were non-normal the non-parametric equivalent test, the Mann-Whitney, was used and the rank sum and p-value were quoted.

Levene's test for homogeneity was used to test the assumption of equal variances. The equal t-value was used when Levene's test value was higher than 0.1. and the unequal t-value was used when it was less than 0.1. The t-value, degrees of freedom, standard error of the difference, 95% confidence intervals and p-values were quoted in both instances.

Carer Multivariate Analysis:

Logistic Regression (LR) was employed to construct a model that would predict the presence of each dependent variable from a number of explanatory variables in the most parsimonious way possible and to control for the effects of confounding variables. Dichotomised non-linear variables with more than two categories (e.g. ethnic origin) were reduced to two categories (e.g. black/white). Logistic Regression can be used for the dichotomised dependent variable (i.e. High v Low EE) when tested with independent variables which are either continuous or binary. LR forces the predicted probability to lie in the range $0 \leq p \leq 1$. LR therefore models the log odds, which can take any real value and its corresponding probability. The Likelihood Method (as opposed to the Wald or Conditional method) was used because it is a more exact method. The Likelihood Method compares models of best fit. The method uses as a criterion for model entry the extent to which an independent variable can predict the presence of the dependent variable when included in a model. It was used in a forward stepwise manner, which finds the variable which has the strongest association with the dependent variable then finds the variable among those not in the model that, when added, explains the largest amount of remaining variability. The stepwise forward method then continues to add variables until the addition of an extra variable is not statistically significant at the $p=0.05$ level.

Explanatory variables were entered in blocks in a hierarchical manner to increase the simplicity and generalisability of the model. The order was as follows: Total questionnaire scores then subscale totals. For example, Avoidant coping was entered before the individual scales of denial, mental disengagement, behavioural disengagement and substance use.

CFI Inter Rater Reliability Statistics Used

Inter-rater reliability (IRR) is commonly defined as the ratio of the true score variance to the observed score variance. It was carried out for Expressed Emotion by randomly selecting nine

of the 46 audio-tapes for Professor Kuipers to rate the tapes blindly. The Intra Class Correlation co-efficient (ICC) was used to examine the ordinal EE ratings.

The Kappa statistic was used when the ratings were dichotomised. Kappa takes into consideration the agreement between raters due to chance and so is often called the 'chance-corrected proportional agreement'. Altman's (1991) modification of Landis and Koch's (1977) guidelines to judge level of agreement under Kappa were used.

Chapter 6:

Overall Sample Descriptive Results

6.1 INTRODUCTION

This chapter describes the overall characteristics of the project sample. First outlined is the overall sample of first episode psychosis patients, including the degree of sample overlap between the life event and EE studies. Described second are the patients in the life event-onset study, almost all of whom also participated in the life event-delusion study. Described third are the patients in the EE study. The fourth section describes the carers in the EE study. Finally, some information is available on people who refused to participate in the project. Discussion of the various issues arising from the descriptive results takes place in Chapter 9.

6.2 SAMPLE SIZES AND OVERLAPS BETWEEN THE THREE STUDIES

Fifty-Eight first episode psychosis patients were involved in the study. Forty-one patients were involved in the event-onset study, 40 in the event-delusional theme study, and 46 patients were included in the EE study. Only one patient (1/41, 2%) involved in the event-onset study did not have delusions and so was not eligible for the delusion study. Forty-eight percent (28/58) of patients participated in both the life event-onset and EE studies, with 21% (12/58) in the life event study only and 31% (18/58) only in the EE study.

6.3 OVERALL PATIENT CHARACTERISTICS

6.3.1 Overall Patient Socio-Demographic Characteristics

Table 6.1 shows the patient socio-demographic characteristics. Sixty-two percent were male and nearly half (46.6%) of the patients were 'black'. The mean age was 31, and there was a very wide age range (46.6, 17.5-64.1). A frequency distribution of the ages indicated that 58% (N=34/58) of the sample were under age 30, and 84% (49/58) were under age 40. There were four outlying values (ages 58.8, 61.0, 62.8, 64.1), of which two

were male and two had a schizophrenia diagnosis. When these outliers were removed from the analysis the mean age was 28.

6.3.2 Overall Patient Illness-Related Characteristics

Table 6.2 sets out the main patient illness-related characteristics. Nearly two-thirds (65.5%) of the patients carried a diagnosis of schizophrenia, and the mean onset age was 30.1. SCAN interviews were conducted as soon as possible after permission was given by the key worker or doctor involved with the patient's care. The time between the emergence of the first positive symptom and the SCAN interview defined the illness length. The mean illness length was 40 weeks and there was a very wide range (321.6 weeks). Male illness length was, on average, 26.1 weeks longer than females (48.9 v 22.7), a statistically significant difference (unequal t-value = 2.0, d.f. = 49.4, 95% C.I. .38, 52.0, $p = 0.04$). Eighty-one percent (47/58) had an illness length less than one year, a further 10% (6/58) had an illness length of less than two years, and a further 9% (5/58) had an illness length of more than two years. One person had been continuously ill and cared for by his (High EOI) mother for over five years. A small number of patients (4/58, 7%) were still delusional at the time of the SCAN interview. Three of them participated in both the life event-onset (3/41, 7%) and event-delusional theme (3/40, 7%) studies. About half the patients were SCAN-interviewed while they were still an inpatient. The rest were interviewed very shortly after discharge, either at the hospital or community base time or at their home.

Table 6.1:
Overall patient sample: sociodemographic characteristics

| | Male | Female | Overall |
|-------------------|--------------------|--------------------|--------------------|
| | N=36 | N=22 | N=58 |
| | (62%) | (38%) | (100%) |
| Patient age | | | |
| Mean (s.d.) | 30.0 (11.8) | 32.6 (10.5) | 31.0 (11.3) |
| Median | 26.7 | 29.9 | 28.1 |
| Min.-Max. (Range) | 17.5 - 64.1 (46.6) | 18.4 - 58.9 (40.4) | 17.5 - 64.1 (46.6) |
| Patient ethnicity | % (N) | % (N) | % (N) |
| ‘black’ | 47.2 (17) | 45.5 (10) | 46.6 (27) |
| ‘white’ | 50.0 (18) | 54.5 (12) | 51.7 (30) |
| ‘unclassified’ | 2.8 (1) | 0 | 1.7 (1) |

Table 6.2:
Overall patient sample: illness-related characteristics

| | Male | Female | Overall |
|------------------------|---------------------|---------------------|--------------------|
| | N=36 | N=22 | N=58 |
| | (62%) | (38%) | (100%) |
| Age at onset | | | |
| Mean (s.d.) | 29.1 (11.6) | 32.6 (10.5) | 30.1 (11.1) |
| Median | 26.1 | 29.9 | 27.3 |
| Min.-Max. (Range) | 17.5 - 64.1 (46.6) | 18.4 - 58.9 (40.4) | 17.5 - 64.1 (46.6) |
| Illness length (weeks) | | | |
| Mean (s.d.) | 48.9 (70.0) | 22.7 (26.8) | 40.0 (57.9) |
| Median | 23.1 | 14.4 | 18.0 |
| Min. Max. (Range) | 1.3 - 322.9 (321.6) | 1.9 - 112.6 (110.7) | 1.3 -322.9 (322.9) |
| Diagnosis | % (N) | % (N) | % (N) |
| schizophrenia / | | | |
| schizoaffective | 63.9 (23) | 68.2 (15) | 65.5 (38) |
| bipolar | 19.4 (7) | 9.1 (2) | 15.5 (9) |
| other psychoses | 16.7 (6) | 22.7 (5) | 19.0 (11) |

6.4 PATIENTS IN THE LIFE EVENT OR EE STUDIES

The main patient difference between the life event sub-sample (tables 6.3 and 6.4) and the overall sample (Tables 6.1 and 6.2) is the illness length, which is both shorter and more similar between the genders than the overall sample. This is due to the event study inclusion criteria that illness length should be a maximum of one year before interview. The patient socio-demographic and illness-related characteristics of the EE sub-sample (Tables 6.5 and 6.6) are similar to the overall sample.

Table 6.3:
Life event patient sample: socio-demographic characteristics

| | Male | Female | Overall |
|-------------------|--------------------|--------------------|--------------------|
| | N=24 | N=17 | N=41 |
| | (58.5%) | (41.5%) | (100%) |
| <hr/> | | | |
| Patient age | | | |
| Mean (s.d.) | 29.8 (11.8) | 30.1 (7.8) | 29.9 (10.3) |
| Median | 26.2 | 29.6 | 26.9 |
| Min.-Max.(Range) | 17.5 - 62.9 (45.4) | 18.4 - 46.7 (28.3) | 17.5 - 62.9 (45.4) |
| | | | |
| Patient ethnicity | % (N) | % (N) | % (N) |
| ‘black’ | 41.7 (10) | 47.1 (8) | 43.9 (18) |
| ‘white’ | 54.2 (13) | 52.9 (9) | 53.7 (22) |
| ‘unclassified’ | 4.1 (1) | 0 | 2.4 (1) |

Table 6.4:
Life event patient sample: illness-related characteristics

| | Male | Female | Overall |
|------------------------|--------------------|--------------------|--------------------|
| | N=24 | N=17 | N=41 |
| | (58.5%) | (41.5%) | (100%) |
| Age at onset | | | |
| Mean (s.d.) | 29.5 (11.8) | 29.8 (7.8) | 29.6 (11.1) |
| Median | 26.1 | 29.3 | 26.7 |
| Min.-Max. (Range) | 17.5 - 62.3 (44.8) | 18.2 - 46.5 (28.4) | 17.5 - 62.3 (44.8) |
| Illness length (weeks) | | | |
| Mean (s.d.) | 20.0 (14.3) | 14.7 (6.4) | 17.2 (11.8) |
| Median | 17.5 | 14.1 | 15.4 |
| Min. Max. (Range) | 1.3 - 51.9 (50.6) | 5.4 - 28.1 (22.7) | 1.3-51.9 (50.6) |
| Diagnosis | % (N) | % (N) | % (N) |
| schizophrenia / | | | |
| schizoaffective | 58.3 (14) | 64.7 (11) | 61.0 (25) |
| bipolar | 25.0 (6) | 11.8 (2) | 19.5 (8) |
| other psychoses | 16.7 (4) | 23.5 (4) | 19.5 (8) |

Table 6.5:
Expressed Emotion patient sample: socio-demographic characteristics

| | Male | Female | Overall |
|-------------------|--------------------|--------------------|--------------------|
| | N=27 | N=19 | N=46 |
| | (58.7%) | (41.3%) | (100%) |
| Patient age | | | |
| Mean (s.d.) | 29.4 (11.8) | 33.2 (11.1) | 31.0 (11.5) |
| Median | 26.6 | 29.9 | 28.1 |
| Min.-Max.(Range) | 17.5 - 64.1 (46.6) | 18.4 - 58.9 (40.4) | 17.5 - 64.1 (46.6) |
| Patient ethnicity | % (N) | % (N) | % (N) |
| ‘black’ | 44.4 (12) | 42.1 (8) | 43.3 (20) |
| ‘white’ | 51.9 (14) | 57.9 (11) | 54.9 (25) |
| ‘unclassified’ | 3.7 (1) | 0 | 2.2 (1) |

Table 6.6:
Expressed Emotion patient sample: illness-related characteristics

| | Male | Female | Overall |
|------------------------|--------------------|--------------------|--------------------|
| | N=27 | N=19 | N=46 |
| | (58.7%) | (41.3%) | (100%) |
| Age at onset | | | |
| Mean (s.d.) | 28.3 (11.4) | 32.8 (11.0) | 30.2 (11.3) |
| Median | 25.1 | 29.9 | 27.3 |
| Min.- Max. (Range) | 17.5 - 62.3 (44.8) | 18.4 - 58.9 (40.4) | 17.5 - 62.3 (44.8) |
| Illness length (weeks) | | | |
| Mean (s.d.) | 57.9 (77.2) | 22.9 (28.9) | 43.4 (63.9) |
| Median | 24.0 | 14.1 | 18.0 |
| Min. Max. (Range) | 1.3 -322.9 (321.6) | 1.9 -112.6 (110.7) | 1.3 -322.9 (321.6) |
| Diagnosis | % (N) | % (N) | % (N) |
| schizophrenia / | | | |
| schizoaffective | 66.7 (18) | 73.7 (14) | 69.6 (32) |
| bipolar | 18.5 (5) | 5.3 (1) | 13.0 (6) |
| other psychoses | 14.8 (4) | 21.1 (4) | 17.4 (8) |

6.5 CARER CHARACTERISTICS

The characteristics of the carers are shown in Tables 6.7 and 6.8. Carers were assessed as soon as possible after the patient's assessment was complete, usually within one week. They were a group of mainly middle-aged (mean age 47, median age 50, standard deviation 14, range 19-72), female (72%), parents (61%). Carers were significantly more likely to be female than male ($p=0.05$, $d.f.=1$, $X^2=3.8$). Most carers (61%) were living with a partner, nearly half (41%) lived alone or just with the patient, nearly a third (61%) were also caring for a child, and nearly half (48%) worked full time. Nearly half (43.5%) of carers were not white. A fifth of carers had had previous experience of caring for someone with a psychiatric problem. Carers were in moderately high face-to-face contact (27.5 hours) with the patient before hospital admission. Almost a third (30%) of carers were in high contact, with just over half (52%) living with the patient. Nearly half the patients (44%) were in hospital when the interview took place and nearly two-thirds (65%) of the interviews were carried out in the carer's home. Nearly half (46%) of the carers interviewed were living with the patient at onset.

Table 6.7
 Carer Socio-Demographic characteristics part 1

| | Male | Female | Overall |
|-------------------------|------------------|------------------|--------------|
| | N=13 | N=33 | N=46 |
| | (28.3%) | (71.7%) | (100%) |
| Age | | | |
| Mean (s.d.) | 46.9 (15.7) | 47.4 (14.1) | 47.2 (14.40) |
| Median | 48.8 | 49.0 | 49.0 |
| Min. Max. (Range) | 23.0 - 68.0 (45) | 19.0 - 72.0 (53) | |
| | % (N) | % (N) | % (N) |
| Ethnicity | | | |
| black | 53.8 (7) | 33.3 (11) | 39.1 (18) |
| white | 46.2 (7) | 60.6 (20) | 56.5 (26) |
| Relationship to patient | | | |
| parent | 38.5 (5) | 68.7 (23) | 60.9 (28) |
| partner | 38.5 (5) | 12.1 (4) | 19.6 (9) |
| sibling | 0 | 6.1 (2) | 4.3 (2) |
| other relative | 15.4 (2) | 6.1 (2) | 8.7 (4) |
| friend | 7.7 (1) | 6.1 (2) | 6.5 (3) |

Table 6.8

Carer Socio-Demographic characteristics part 2

| | Male | | Female | | Overall | |
|-----------------------|---------|--------|---------|------|---------|--------|
| | N=13 | | N=33 | | N=46 | |
| | (28.3%) | | (71.7%) | | (100%) | |
| <hr/> | | | | | | |
| Face-to-face-contact | | | | | | |
| hrs/wk: | | | | | | |
| mean (s.d.) | 28.0 | (27.6) | 25.8 | 27.8 | 26.4 | (14.4) |
| | % | (N) | % | (N) | % | (N) |
| High face-to-face- | | | | | | |
| contact (>35 hrs/wk) | 23.1 | (3) | 60.6 | (20) | 32.6 | (15) |
| Lives with patient | | | | | | |
| no | 46.2 | (6) | 48.5 | (16) | 47.8 | (22) |
| yes | 53.8 | (13) | 51.5 | (17) | 52.2 | (24) |
| Living with a partner | | | | | | |
| no | 30.8 | (4) | 42.4 | (14) | 28.3 | (13) |
| yes | 69.2 | (9) | 57.6 | (19) | 60.9 | (28) |
| Employed | | | | | | |
| no | 46.2 | (6) | 36.4 | (12) | 39.1 | (18) |
| yes | 53.8 | (7) | 63.6 | (21) | 60.9 | (28) |

6.6 PARTICIPANT REFUSALS

Fifty-eight first episode psychosis patients took part in either the life event or EE studies. Five patients were recorded as refusing to participate for the life event study and five patients were recorded as refusing to participate in at least one part of the EE study. However, information on the people who refused (age, gender and ethnicity) was recorded for the life event and EE studies separately. Also, the age, gender and ethnicity of the patients who refused to participate in the EE study, were not recorded. This meant it was not possible to pool the information for an overall refusal rate and compare those who refused with those who consented. Therefore the total patient refusal rate is at least 7.9% (5/63) and at most 14.7% (10/68). Age, gender and ethnicity information is, however, available separately for patients who refused the life event study, and for carers who refused the EE study.

The life event study sample size was 41. Five refused to participate, giving a refusal rate of 11% (5/46). The age, sex and ethnic origin of the people in the delusion study who did not consent were compared with those who did. The low number of people who refused did not justify inferential tests and was better examined using a descriptive approach. People who refused to participate were slightly older than people who agreed (mean age 32 v 29). Males were over-represented in those who refused (4/5, 80% versus 57%). Black people were also over-represented among those who refused (60% v 45%). There was very little missing data. It was not possible to classify one patient's delusions as persecutory or not. Two other patients with persecutory delusions appeared to have experienced an intrusive event of at least moderate severity, but verification of the event was not possible, so the two events were not included in the delusion analysis.

Forty-six patient-carer pairs were involved in the EE study. Three patients who were in contact with a carer refused to participate in the study. Two other patients refused to participate but gave permission for their carer to be assessed. Thus the patient refusal rate was 10% (5/51) for the EE analysis including patient symptom (SCAN) data and 6% (3/49) for the EE analysis minus the patient symptom data. The details (gender, age and

ethnicity) of the five patients who refused permission for either the SCAN or the carer assessment were not recorded. Three carers whose patient had agreed to participate were not assessed, so the carer refusal rate was 6% (3/49). If the carers who refused are added to the carers who were not assessed because their patient refused, this yields an unassessed carer proportion of 11.5% (6/52), or 15% (8/53) if SCAN data is included in the calculation.

The carer groups who refused and consented were compared on sex, age and ethnicity. The groups were similar in all respects (consenters mean age 31, refusers 28; consenters gender 59% male, refusers 60% male), except that the three carers who refused were all black, compared to only 34.5% of the consenting group who were black. Additionally, all these three carers had previously cared for another relative who had previously been diagnosed with a psychotic disorder, compared to 20% of the consenting group. There was very little missing data, with just two SCANS (from Low EE carers), one face-to-face contact score (from a High EE carer) and three Social Functioning Scale scores (all from Low EE carers) not collected.

6.7 SUMMARY OF THE DESCRIPTIVE CHARACTERISTICS OF THE SAMPLE

The overall patient sample was 58, with 41 in the life event-onset study, 40 in the life event–delusion study, and 46 in the EE study. Forty-eight percent (28/58) of patients participated in both the life event-onset and EE studies, with 21% (12/58) in the life event study only and 31% (18/58) in the EE study only. The patient sample was nearly two-thirds male, fairly young, and nearly half were ‘black’. The median illness length was 18 weeks, although outliers pushed the mean illness length up to 40 weeks. Females had a significantly shorter illness duration. Two-thirds of patients were classified as having a schizophrenia diagnosis. The life event sample had a much shorter illness length than the overall sample, and the EE sample characteristics were similar to the overall sample.

The 46 carers were mainly middle-aged, parental, female, in moderately high face-to-face contact, and nearly half of the interviews took place while the patient was in hospital. Information was not collected in a way which permitted an exact calculation of an overall refusal rate, however the figure lay between 7.9% (5/63) and 14.7% (10/68). The patient refusal rate for the life event-onset study was 11% (5/41), and for the EE study it was 10% (5/51). There was a slight over-representation of black males in the group who refused. There was very little missing data.

Chapter 7

Results of Stressful Life Events and the Onset of Psychosis and Delusional Theme

7.1 INTRODUCTION

This chapter presents the results of both the stressful life event-onset study and the stressful life event-delusion study. The LEDS inter-rater reliability results are discussed first. Presented next are the descriptive overall rate of events in the year before first episode psychosis, including the rate of particular types of events. A graphical and statistical investigation is conducted to see if events cluster near to onset, including an examination by levels of independence and severity. The prevalence of different types of delusional theme in the sample is presented and the hypothesis that intrusive events predict persecutory delusions is then tested.

7.2 LEDS INTER-RATER RELIABILITY

The formal inter-rater reliability of the LEDS scores was checked. Approximately one third (14/41) of cases were checked by Tirril Harris and a panel at several meetings during the duration of the project, and the ratings were deemed acceptable. The self-esteem scale is a new measure. Twenty events spanning the range of scores on this dimension were used to check reliability. Results indicated that there was agreement of the score (1, 2, 3 or 4) in 19/20 events, and perfect agreement for events of marked/moderate severity.

7.3 DESCRIPTION OF EVENTS

7.3.1 The Prevalence of Stressful Events in the Whole Sample

The prevalence of stressful life events before first episode psychosis within the entire sample is shown in Tables 7.1-7.12. Each type of event (threat, danger, loss, self-esteem, humiliation and intrusiveness) is shown in a different table. The *number of events* and the *numbers of people who had at least one event* are shown in separate tables for each type of event. In each table, separate figures are shown for a) events rated at least 3 on severity b) events rated at least 3 on severity that were independent c) events rated 1 or 2 on severity (c.f. Bebbington et al., 1993) d) events rated 1 or 2 on severity that were independent. Event rates were calculated over the

full one year before onset (c.f. Jacobs & Myers, 1976), the final three-month period (c.f. Day et al., 1987) and the final three-week period (c.f. Al-Khani et al., 1986).

As with other studies, the event rates refer only to events rated on long-term stress (minimum 14 days) on the LEDS. Short term events were not analysed: the LEDS technology does not permit rating short-term events on most of the various stress dimensions, and in any case the very concept of short-term stress implies limited effect. Only events of at least moderate severity can be rated on Humiliation. Although the present study makes no hypotheses about events other than intrusive events, their prevalence is given in Tables 7.11 and 7.12 because the information has not previously been reported in the literature, and the event types are used for the planned event-theme specificity testing.

It can be seen from Tables 7.1 and 7.2 that stressful life events were highly prevalent before the first episode of psychosis. Table 7.1 shows that the 41 patients had a total of 185 stressful life events in the year before onset. The mean event rate was thus 4.5 over the year, dropping to 2.3 when only independent events were included. Table 7.2 shows that three-quarters of the sample experienced at least one independent event in the year before onset. Nearly half (43.9%) had an independent event in the final 12 weeks before onset, and just over a third (34.1%) experienced an independent event of at least moderate severity in that period. Nearly one in five patients (19.5%) experienced an independent event in the final 3 weeks. All types of events (intrusive, loss, self-esteem, humiliating and danger) were experienced by the sample in all three periods before onset.

Table 7.1: Number of Threat events in three different periods before first episode psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|-------------------------------------|------------|----------------|---------------|
| | N (Mean) | N (Mean) | N (Mean) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1, 2, or 3 | 185 (4.51) | 57 (1.39) | 18 (0.44) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 96 (2.34) | 33 (0.80) | 9 (0.22) |
| Indep. / Possibly Indep.events | | | |
| Severity 1 or 2 | 97 (2.37) | 30 (0.80) | 9 (0.22) |
| Indep. events. | | | |
| Severity 1 or 2 | 57 (1.39) | 21 (0.51) | 6 (0.15) |

Table 7.2: Numbers and percentages of people who experienced *at least one* Threat event in three different periods before first episode psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|---------------------|-----------|----------------|---------------|
| | N (%) | N (%) | N (%) |
| Indep. / Possibly. | | | |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 39 (95.1) | 26 (63.4) | 12 (29.3) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 31 (75.6) | 18 (43.9) | 8 (19.5) |
| Indep. / Possibly | | | |
| Indep. events. | | | |
| Severity 1 or 2 | 34 (82.9) | 19 (46.3) | 9 (22.0) |
| Indep. Events. | | | |
| Severity 1 or 2 | 24 (58.5) | 14 (34.1) | 6 (14.6) |

Table 7.3: Number of Intrusive events in three different periods before first episode psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|---------------------|-----------|----------------|---------------|
| | N (Mean) | N(Mean) | N (Mean) |
| Indep. / Possibly | | | |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 83 (1.29) | 30 (0.73) | 10 (0.24) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 40 (0.98) | 14 (0.34) | 4 (0.10) |
| Indep. / Possibly | | | |
| Indep. events. | | | |
| Severity 1 or 2 | 53 (1.29) | 18 (0.44) | 9 (0.22) |
| Indep. events. | | | |
| Severity 1 or 2 | 26 (0.63) | 8 (0.20) | 4 (0.10) |

Table 7.4: Numbers and percentages of people who experienced *at least one* Intrusive event in three different periods before first episode psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|---------------------|-----------|----------------|---------------|
| | N (%) | N (%) | N (%) |
| Indep. / Possibly | | | |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 30 (73.2) | 19 (46.3) | 8 (19.5) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 21 (51.2) | 11 (26.8) | 4 (9.8) |
| Indep. / Possibly | | | |
| Indep. events. | | | |
| Severity 1 or 2 | 22 (53.7) | 14 (34.1) | 8 (19.5) |
| Indep. events. | | | |
| Severity 1 or 2 | 14 (34.1) | 7 (17.1) | 4 (9.8) |

Table 7.5: Number of Loss events in three different periods before first episode psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|-------------------------------------|-----------|----------------|---------------|
| | N (Mean) | N (Mean) | N (Mean) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1, 2, or 3 | 59 (1.44) | 23 (0.56) | 6 (0.15) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 39 (0.95) | 16 (0.39) | 4 (0.10) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1 or 2 | 41 (1.00) | 16 (0.39) | 6 (0.15) |
| Indep. events. | | | |
| Severity 1 or 2 | 28 (0.68) | 11 (0.27) | 4 (0.10) |

Table 7.6: Numbers and percentages of people who experienced *at least one* Loss event in three different periods before first episode psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|-------------------------------------|-----------|----------------|---------------|
| | N (%) | N (%) | N (%) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1, 2, or 3 | 26 (63.4) | 14 (34.1) | 6 (14.6) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 21 (51.2) | 12 (29.3) | 4 (9.8) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1 or 2 | 18 (43.9) | 11 (26.8) | 6 (14.6) |
| Indep. events | | | |
| Severity 1 or 2 | 14 (34.1) | 8 (19.5) | 4 (9.8) |

Table 7.7: Number of Self-Esteem events in three different periods before first episode psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|-------------------------------------|-----------|----------------|---------------|
| | N (Mean) | N (Mean) | N (Mean) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1, 2, or 3 | 63 (1.54) | 20 (0.49) | 9 (0.22) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 33 (0.80) | 9 (0.22) | 5 (0.12) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1 or 2 | 30 (0.73) | 9 (0.22) | 6 (0.15) |
| Indep. events. | | | |
| Severity 1 or 2 | 15 (0.37) | 4 (0.10) | 5 (0.12) |

Table 7.8: Numbers and percentages of people who experienced *at least one* Self-Esteem event in three different periods before first psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|-------------------------------------|-----------|----------------|---------------|
| | N (%) | N (%) | N (%) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1, 2, or 3 | 29 (70.0) | 15 (36.6) | 8 (19.5) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 19 (46.3) | 9 (22.0) | 5 (12.2) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1 or 2 | 17 (41.5) | 9 (22.0) | 6 (14.6) |
| Indep. events. | | | |
| Severity 1 or 2 | 10 (24.4) | 4 (9.8) | 3 (7.3) |

Table 7.9: Number of Humiliating events in three different periods before first episode psychosis (Humiliating events only rateable in LEDS if 1 or 2 severity) (N=41).

| Event Type | One Year | Final 12 | Final 3 |
|-------------------|-----------|-----------|----------|
| | | weeks | weeks |
| | N (Mean) | N (Mean) | N (Mean) |
| Indep. / Possibly | | | |
| Indep. events. | | | |
| Severity 1 or 2 | 42 (1.02) | 15 (0.37) | 6 (0.15) |
| Indep. events. | | | |
| Severity 1 or 2 | 23 (0.56) | 8 (0.20) | 3 (0.07) |

Table 7.10: Numbers and percentages of people who experienced at *least one* Humiliating event in three different periods before first episode psychosis (Humiliating events are only rated in LEDS if 1 or 2 on severity) (N=41).

| Event Type | One Year | Final 12 | Final 3 |
|-------------------|-----------|-----------|----------|
| | | weeks | weeks |
| | N (%) | N (%) | N(%) |
| Indep. / Possibly | | | |
| Indep. events. | | | |
| Severity 1 or 2 | 19 (46.5) | 10 (24.1) | 6 (14.6) |
| Indep. events. | | | |
| Severity 1 or 2 | 10 (24.4) | 5 (12.2) | 3 (7.3) |

Table 7.11: Number of Danger events in three different periods before first episode psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|---------------------|-----------|----------------|---------------|
| | N (Mean) | N (Mean) | N (Mean) |
| Indep. / Possibly | | | |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 86 (2.10) | 23 (0.56) | 5 (0.12) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 50 (1.22) | 16 (0.39) | 2 (0.05) |
| Indep. / Possibly | | | |
| Indep. events. | 65 (1.59) | 15 (0.37) | 3 (0.07) |
| Severity 1 or 2 | | | |
| Indep. events. | | | |
| Severity 1 or 2 | 40 (0.98) | 12 (0.29) | 2 (0.05) |

Table 7.12: Numbers and percentages of people who experienced at *least one* Danger event in three different periods before first episode psychosis (N=41).

| Event Type | One Year | Final 12 weeks | Final 3 weeks |
|-------------------------------------|-----------|----------------|---------------|
| | N (%) | N (%) | N (%) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1, 2, or 3 | 31 (75.6) | 15 (36.6) | 5 (12.2) |
| Indep. events. | | | |
| Severity 1, 2, or 3 | 21 (51.2) | 11 (26.8) | 2 (4.9) |
| Indep. / Possibly Indep. events. | | | |
| Severity 1 or 2 | 27 (65.9) | 11 (26.8) | 3 (7.3) |
| Indep. events. | | | |
| Severity 1 or 2 | 17 (41.5) | 8 (19.5) | 2 (4.9) |

7.3.2 How Common were Intrusive Events?

Intrusive events (see Tables 7.3 and 7.5) are of particular relevance for theories of vulnerability to psychosis (Harris, 1991; Day et al., 1987). It is therefore noteworthy that independent intrusive events occurred in just over half (51.2%) of the sample, with just over a third (34.1%) experiencing an independent intrusive event of marked/moderate severity. Just over a quarter (26.8%) experienced an independent intrusive event in the final 12 weeks. However, they were not obviously more common than independent loss, self-esteem or danger events in any of the three periods. In addition, people who experienced intrusive events also commonly experienced other types of events (Table 7.13). Only two people experienced at least one intrusive event without also experiencing another type of stress, be it from the intrusive event itself, or from a separate event.

Table 7.13

Proportions of people who experienced at least one intrusive event, with and without experiencing at least one other type of event, in the year before onset.

| | % | (N) |
|--|----|------|
| All Intrusive events | 73 | (30) |
| Intrusive event plus Danger event | 61 | (25) |
| Intrusive event plus Loss event | 51 | (21) |
| Intrusive event plus Self-Esteem event | 63 | (26) |
| Intrusive event plus (moderate/marked) Humiliation event | 63 | (26) |
| Intrusive event alone | 5 | (2) |

7.3.3 Did Events Cluster In the Period Nearest to Onset?

It will be recalled from Chapter Two that several (but not all) stressful life event studies on psychosis have found that events clustered close to onset. In order to display this possibility, the numbers of events and the numbers of people experiencing at least one event were examined graphically by dividing the one year before onset into four 3-month categories. The final three months was then compared with an aggregated mean score for the other three periods so that a Wilcoxon test for two related samples could be used. A second analysis involved dividing the final 12 *weeks* into four three-week periods and repeating the graphical and statistical procedures. Each analysis was repeated for total threat events (i.e. independent and possibly independent, 1, 2 or 3 on severity), total 'more severe' threat events (i.e. independent and possibly independent, 1 or 2 on severity), total independent threat events (i.e. independent and 1 or 2 or 3 on severity) and total independent 'more severe' events (i.e. independent and 1 or 2 on severity).

(i) Clustering Over One Year

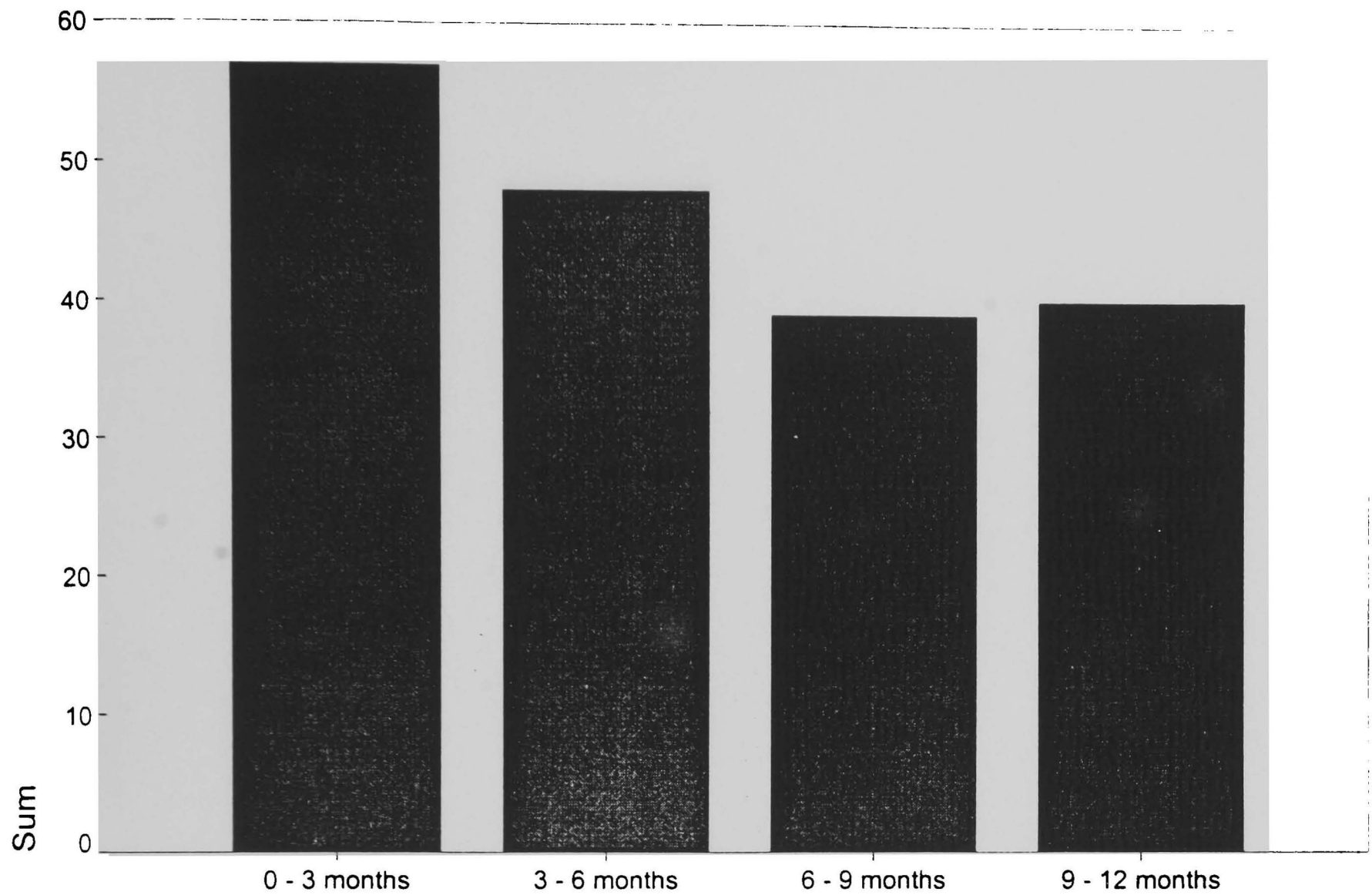
The number of threat events (total number, number of marked/moderate, number of independent and number of independent marked/moderate events) occurring in the four 3-month periods before onset are represented in Graphs 7.1-7.4. The results of the corresponding Wilcoxon tests appear in table 7.13. The number of people who experienced at least one threat event was also graphed, and their corresponding Wilcoxon results shown in Table 7.14. Graph 7.5 represents the number of people who experienced at least one independent threat of marked/moderate severity in the four three month periods before onset. All five analyses indicate that events are more frequent for the three months before onset compared to the preceding nine months. In terms of statistical significance, there were appreciable trends for the total number of threat events ($p=0.06$) and total number of independent events of at least moderate (i.e. 1 or 2) severity ($p=0.09$) to be higher in the final three months. The one statistically significant result was that more people experienced at least one independent threat of marked/moderate severity event in the final three months compared to the mean score of the other nine months ($p=0.04$). Events therefore do tend to cluster nearer to onset. Furthermore, the clustering remains even when confined to independent and more severe events; indeed the

clustering tends to be more statistically significant, not less, for this combination of event characteristics.

(ii) Clustering over the Final Twelve Weeks

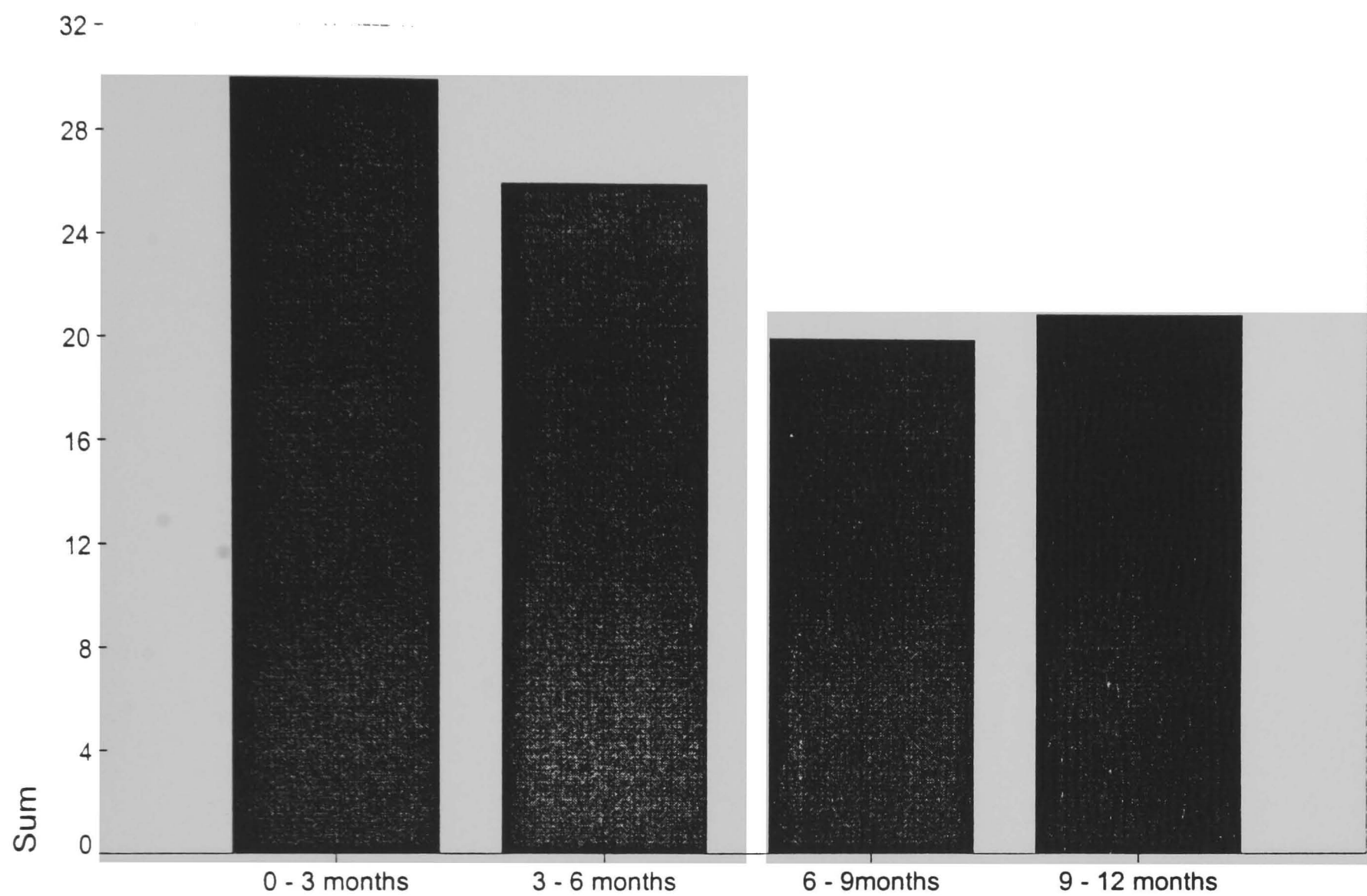
The graphical and statistical procedures used to compare the final three months with the previous nine months were repeated for the final three weeks compared to the preceding nine weeks. Table 7.13 shows the Wilcoxon results. In summary, the graphs did not always show that events clustered in the final three weeks and though every mean rank was higher in the final three weeks, the Wilcoxon results indicated no statistically significant or trend results.

Graph 7.1: No. of threat events rated
1, 2, or 3 in four three month periods



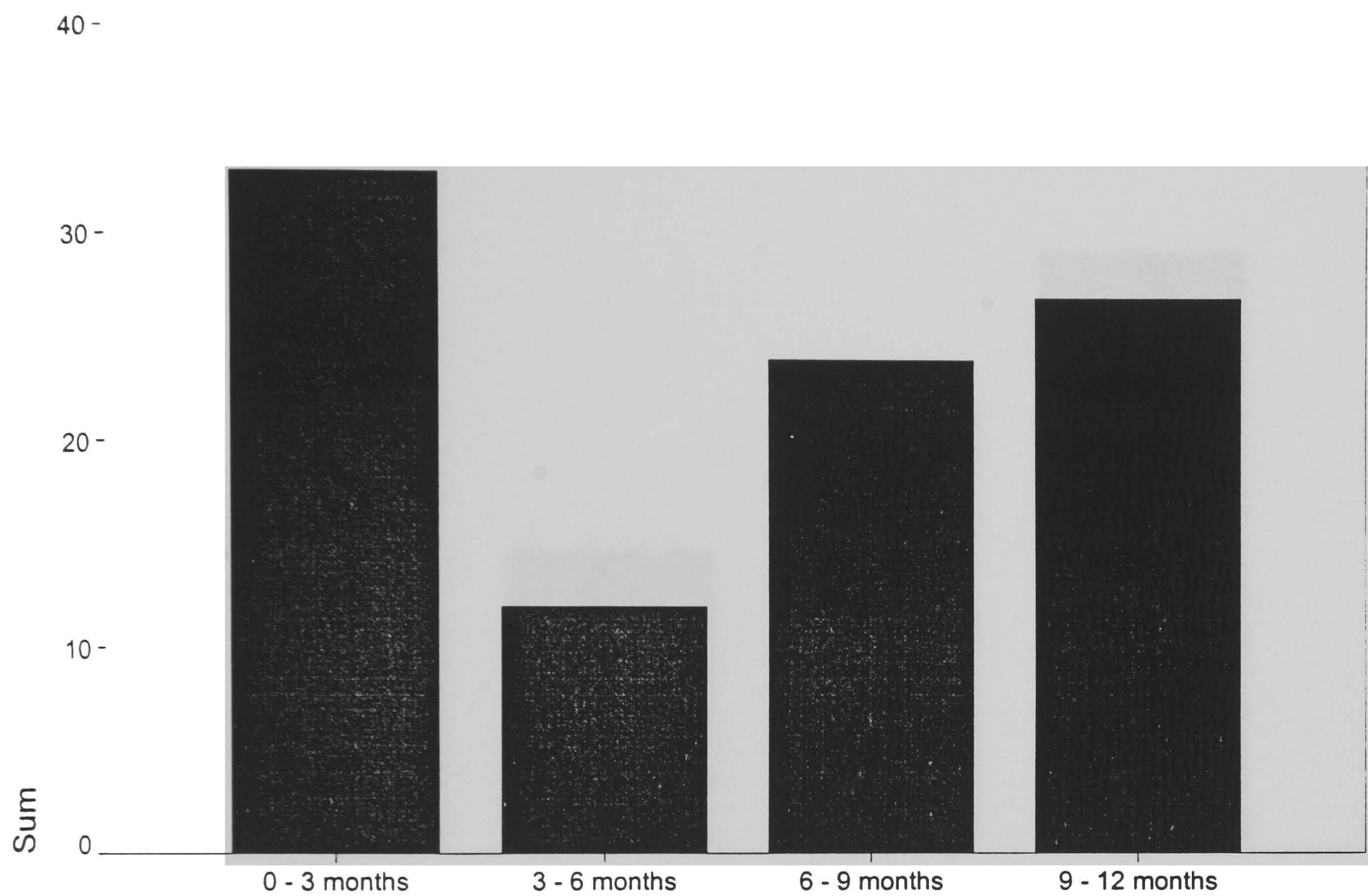
The left hand bar is closest to onset

Graph 7.2: No. of threat events rated
1 or 2 in four three month periods



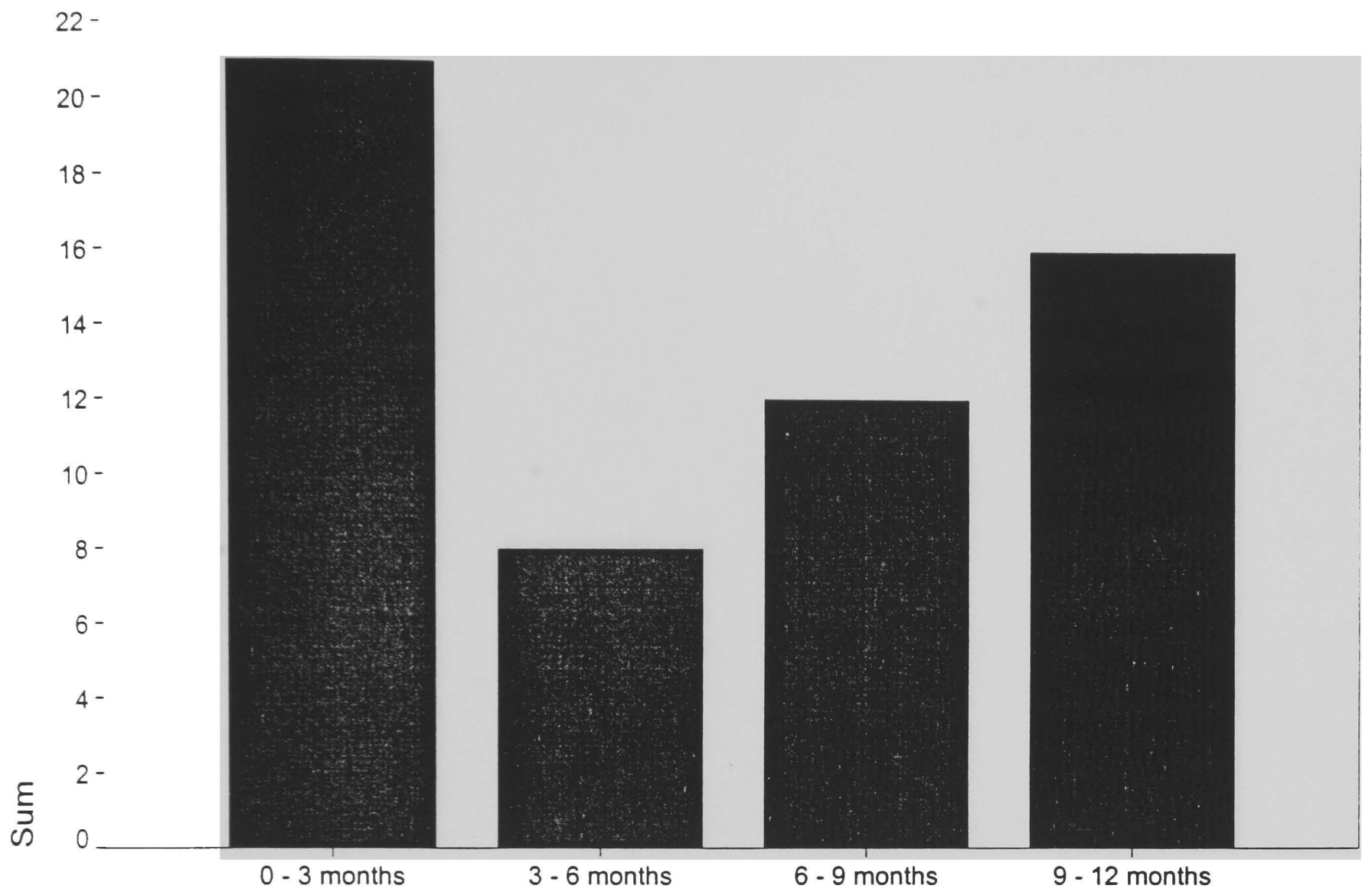
The left hand bar is closest to onset.

Graph 7.3: No. of independent threat events
rated 1, 2, or 3 in four three month periods



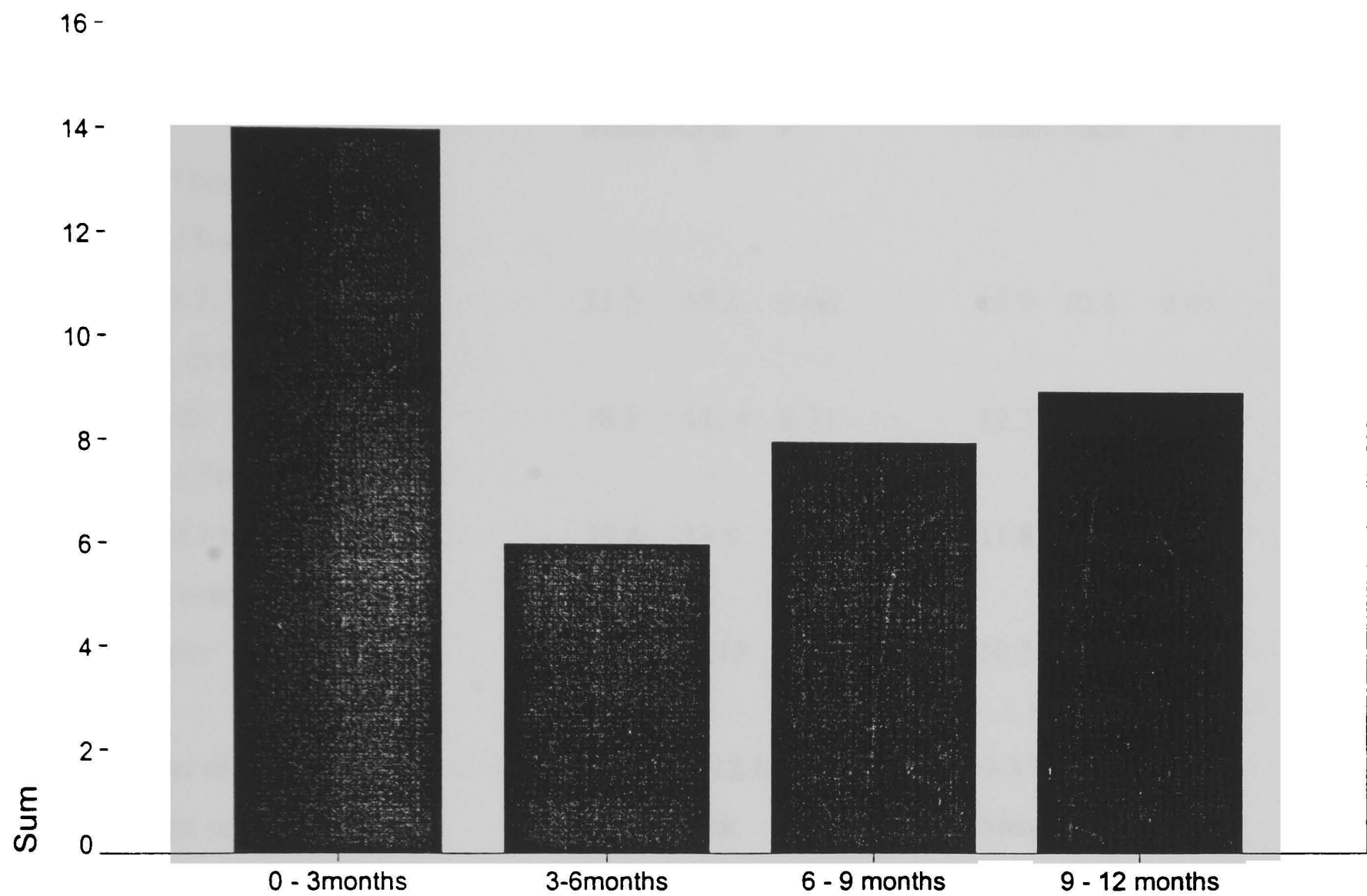
The left hand bar is closest to onset.

Graph 7.4: No. of independent threat events
rated 1 or 2 in four three month periods



The left hand bar is closest to onset.

Graph 7.5: No. of people with an independent threat event rated 1 or 2 (N=41)



The left hand bar is closest to onset.

Table 7.14: Analysis of event clustering in the three months or three weeks before onset

| Number of Threat Events | 0-3 V 3-12 Months | | | 0-3 V 3-12 Weeks | | |
|----------------------------|-------------------|------|-------|------------------|------|------|
| | Mean-Rank | | P | Mean-Rank | | P |
| Event Type | | | | | | |
| Indep. / Possibly Indep. | | | | | | |
| events 1, 2, or 3 Severity | 21.5 | 15.3 | 0.06 | 15.9 | 10.4 | 0.45 |
| Indep. events 1, 2, or 3 | | | | | | |
| Severity | 18.9 | 11.4 | 0.31 | 12.3 | 6.67 | 0.27 |
| Indep. / Possibly Indep. | | | | | | |
| events 1 or 2 Severity | 19.8 | 13.9 | 0.80 | 11.8 | 7.7 | 0.71 |
| Indep. events 1 or 2 | | | | | | |
| Severity | 14.9 | 9.15 | 0.09 | 10.3 | 5.38 | 0.55 |
| Number of People with | | | | | | |
| at least one threat event | | | | | | |
| Event Type | 0-3 V 3-12 Months | | | 0-3 V 3-12 Weeks | | |
| | Mean-Rank | | P | Mean-Rank | | P |
| Indep. / Possibly Indep. | | | | | | |
| events 1, 2, or 3 Severity | 20.7 | 13.6 | 0.92 | 15.3 | 10.9 | 0.58 |
| Indep. events 1, 2, or 3 | | | | | | |
| Severity | 19.6 | 13.9 | 0.20 | 12.8 | 6.2 | 0.19 |
| Indep. / Possibly Indep. | | | | | | |
| events 1 or 2 Severity | 17.5 | 11.0 | 0.18 | 12.5 | 7.1 | 0.53 |
| Indep. Events 1 or 2 | | | | | | |
| Severity | 15.7 | 8.1 | 0.04* | 10.8 | 5.0 | 0.43 |

* significant at the 5% level (Wilcoxon test for two related samples)

7.4 STRESSFUL LIFE EVENTS AND DELUSIONAL THEME

This section describes the prevalence of delusional themes in the sample and the next tests the hypothesis that intrusive stressful events before onset will predict the development of a persecutory delusional theme.

7.4.1 Prevalence of Themes at First Episode Psychosis

Table 7.15 shows the prevalence of delusional themes in the sample. It can be seen that reference and persecutory themes were highly prevalent, both individually (98%, 87%) and together (85%). Grandiose and depressive themes in the same patient were uncommon (8%). None of the people had a persecutory or a grandiose or depressive theme alone, and only two people had a reference theme without the presence of at least one other theme. The prevalence of themes indicate that both those with persecutory delusions and those without were very likely to express reference, grandiose and depressive delusional themes. However, since no hypotheses are made about intrusive events linking with other types of themes, the co-occurrence of themes does not undermine the validity of the comparison.

Table 7.15: Prevalence of the four delusional themes at first episode psychosis (N=39¹)

| | N (%) |
|--|---------|
| Total Persecutory | 34 (87) |
| Persecutory and Reference | 33 (85) |
| Persecutory and Depressive | 11 (28) |
| Persecutory and Grandiose | 13 (33) |
| Persecutory and Grandiose and Reference | 13 (33) |
| Persecutory and Reference and Depressive | 10 (25) |
| Persecutory alone | 0 |
| Total Grandiose | 17 (43) |
| Grandiose and Reference | 17 (43) |
| Grandiose and Depressive | 3 (8) |
| Grandiose and Depressive and Reference | 3 (8) |
| Grandiose alone | 0 |
| Total Depressive | 11 (28) |
| Depressive and Reference | 10 (25) |
| Depressive alone | 0 |
| Total Reference | 39 (98) |
| Reference alone | 2 (5) |

¹ One person’s theme was unclassifiable as persecutory or otherwise.

7.4.2 Stressful Life Events and Delusional Theme

Both the persecutory and non-persecutory group experienced intrusive events in the year before onset, as shown in Tables 7.16 and 7.17. It can be seen that over a one year period, the main differences emerge in relation to the independence rather than the severity of events. Given that the events were not normally distributed, the overall event rate in the persecutory group was compared with the non-persecutory group using the Mann-Whitney U test. The second statistic, the number of people who experienced at least one event, was tested against the non-persecutory group using the Chi Square statistic. Three periods were tested: one year, three months and three weeks before onset. Analyses were carried out using both levels of severity (i.e. 1 or 2; or 3) and both levels of independence (i.e. independent/independent or possibly independent).

Table 7.18 shows the two main intrusive event–persecutory theme results. The small number of people who lacked a persecutory theme reduced the power of the study to detect differences. However, consistent with the hypothesis, people with persecutory delusions experienced a higher number of intrusive events of all types. In terms of statistical significance, there was a trend (0.09) for people who had a persecutory theme to have experienced a higher number of independent intrusive events of marked or moderate severity. None of the five people without a persecutory delusional theme experienced an intrusive event of this type in the year before onset. This compares with nearly half (14/34, 41.1%) of the persecutory group. However, a two-tailed Fisher’s test showed this failed to reach conventional levels of statistical significance. As with the event-onset study, discrimination was best when based upon the combination of independence and marked/moderate severity.

Table 7.16

The mean number of intrusive events in the persecutory and non-persecutory groups in the year before onset.

| | Persecutory | Other Themes |
|----------------------------|-------------|--------------|
| | Mean | Mean |
| All Intrusive events | 2.1 | 1.8 |
| Intrusive Independent | 1.1 | 0.2 |
| Intrusive Marked/Moderate | | |
| Severity | 1.4 | 0.8 |
| Intrusive Independent with | | |
| Marked/Moderate Severity | 0.8 | 0 |

Table 7.17

Proportions of patients in the persecutory and non-persecutory group who experienced at least one intrusive event in the year before onset

| | Persecutory | | Other Themes | |
|----------------------------|-------------|---------|--------------|-------|
| | % | (N) | % | (N) |
| All Intrusive events | 74 | (25/34) | 60 | (3/5) |
| Intrusive Independent | 53 | (18/34) | 20 | (1/5) |
| Intrusive Marked/Moderate | | | | |
| Severity | 59 | (20/34) | 40 | (2/5) |
| Intrusive Independent with | | | | |
| Marked/Moderate Severity | 41 | (14/34) | 0 | |

7.4.3 Specificity Testing of Intrusive Events and Persecutory Theme

In order to examine the event-specificity of the excess of intrusive events in the persecutory group, intrusive events were tested with both grandiose and depressive delusional themes. (Reference themes were too common for this to be possible). There was absolutely no association. Then in order to test the theme-specificity of the excess of persecutory themes in the intrusive event group, all other event types (danger, loss, self-esteem, humiliation and threat) were tested against the persecutory themes. Again, there was no association. Further, no event type demonstrated the intrusive event finding of a zero proportion of people in the non-persecutory group over the one year before onset. Thus intrusive events are not associated with depressive or grandiose themes, and no other event types are associated with persecutory themes. This was despite the extra power afforded in these to the other tests due to the larger numbers in the comparison groups. The two main findings may therefore have some degree of both theme-specificity and event-specificity.

Table 7.18: The relationship between persecutory delusional theme and intrusive events (independent, of severity 1 or 2) in the year before onset.

| | Theme Absent | Theme Present | P |
|------------------------------------|---------------------------|------------------|--------|
| | Mean Rate (Wilcoxon test) | | |
| Rate of events | 13.0 | 21.0 | 0.09 |
| | Fischer's exact test | | |
| Proportion with at least one event | 0 % (0/5) | 41.1% (14/34) | p=0.13 |

7.5 SUMMARY OF CHAPTER 7

This chapter has presented the results of the stressful life event–onset and intrusive event–persecutory theme studies. With the onset study, the sample size was 41, there was a low refusal rate (10%) and very few missing data. Stressful life events were very frequent before the first episode of psychosis. The 41 people experienced 185 events, 96 of which were independent. Independent events of a marked/moderate severity were clustered at a statistically significant rate in the final three months before onset compared to the preceding nine months. There was no statistically significant clustering in the final three weeks compared to the preceding nine weeks, although the rates were higher in all analyses in the final three weeks. New data were presented about the types of events that befall people before the first episode. Intrusive events were common, but so were all the other event types. Indeed, in the year before onset, people who had experienced at least one intrusive event had also commonly experienced at least one of the other event types too.

In the intrusive event–delusional theme study, the sample size was 39. All four delusional themes assessed were commonly found at the first episode. Theme co-morbidity was also common. The small number of people without a persecutory theme reduced the power of the statistical tests. However, consistent with the hypothesis, people who had a persecutory theme did experience more intrusive events than those without this theme. Results showed a trend for a greater number of events of marked/moderate severity which were independent; none of the five people without a persecutory theme experienced such an event whereas 41% of those experiencing the theme had suffered such a stressor. Tests showed that intrusive events showed no significant or trend associations with grandiose or depressive themes, and none of the other event types showed an association with a persecutory theme. Therefore the intrusive-persecutory results may have some degree of event specificity and theme specificity.

Chapter 8:

Expressed Emotion Results

8.1 INTRODUCTION

Expressed Emotion was tested for its association with the hypothesised carer appraisal variables. It was also tested with the illness-related variables, so that if any proved to be significant they could be used to test if carer appraisal factors would be stronger independent predictors of EE. In line with some past studies, some of the variables were analysed in terms of both a total score and sub-scale scores, for example burden total and the eight burden sub-scales. This approach yields more specific and potentially clinically useful information about EE's correlates. Carers were divided into those with High EE and those who were Low EE and their scores on each variable were compared. Since the literature indicated that correlates of EE may differ according to the measure of EE, all four measures of High EE (Overall High EE, High CC, High EOI and Hostility) were tested with each explanatory variable against the Low EE group. It was also possible to examine the relationship of High CC between the explanatory variables when High EOI was not co-morbidly present. This is a potentially useful analysis to further understand the specificity of appraisal between carers who are High CC compared to those who are High EOI. Thus the explanatory variables were tested with five not four measures of High EE. It would have also been useful to conduct testing using a High EOI alone group, which might also have shed light on any differences between High EOI and High CC, but there was an insufficient number of such carers. Finally, in order to identify the strongest predictors of each measure of High EE, multivariate analyses (logistic regressions) were conducted using only variables that were significant at the 5% level in the univariate analyses. The logistic regressions had the potential to test whether appraisal variables were stronger independent predictors of EE status than illness-related factors.

The EE results are organised into three sections: Section one reports the levels and distribution of EE in the sample as well as the inter-relationship between the EE

components. Section two contains the results of the univariate analyses, which tested each explanatory variable with each measure of EE. Finally, section three contains the multivariate results of each measure of EE and a summary of the EE results as a whole.

8.2 SECTION ONE: EXPRESSED EMOTION DESCRIPTIVE RESULTS

This section presents the carer sample descriptive EE Results. These comprise the EE inter-rater reliability results, the levels and distribution of EE and the inter-relationship between the EE components.

8.2.1 Expressed Emotion Inter-Rater Reliability Results

Inter-rater reliability with Professor Kuipers produced the following results High Intra-Class correlations were obtained for all three key EE scales tested as continuous variables (CC=0.88; H = 0.79[coded as 0=0,1=1,2=1,3=2]); EOI = 0.74). Landis and Koch's (1977) interpretation guidelines that have been revised by Altman (1991, p.404) were used to interpret the dichotomised EE inter-rater reliability: These indicated that Moderate kappa scores were found for the dichotomised scales of Overall EE (0.55) and CC (0.52), and good kappa scores were found for EOI (0.72) and Hostility (0.80 - weighted kappa) .

8.2.2 Levels and Distribution of Expressed Emotion

The EE descriptive results were analysed in terms of proportions of EE (Tables 8.1, 8.2 and 8.3), means scores of EE (Table 8.4) and the inter-correlations between EE components (Table 8.5).

(i) Proportions of EE

Proportions of carers who were High and Low on EE are shown in Tables 8.1, 8.2 and 8.3. It can be seen that nearly half (44%) of the carers were High EE, with nearly one third (32.6%) High EE by CC, nearly a third (30%) Hostile and just over a fifth (21%) displayed High EOI. Very few carers were rated as high on one measure of EE in the absence of scoring high on one of the other EE measures. None of the carers were Hostile alone, only 4% were High CC alone and only 9% were EOI alone. Just over a quarter

(28%) of carers were Critical and Hostile, although few were High CC and High EOI or high on all three EE components (both proportions were 11%). However, of the 10 people rated High EOI, 60% were also rated high on CC and Hostility. With respect to gender differences, male and female carers had similar proportions on the Low and High EE measures except for the fact that all 13 High EOI carers were women.

Table 8.1 Proportions of carers who were High and Low EE

| | Male | | Female | | Total | |
|-------------------|------|--------|--------|--------|-------|--------|
| | N | % | N | % | N | % |
| | 13 | (28.3) | 33 | (71.7) | 46 | (100) |
| EE status | | | | | | |
| low | 9 | (69.2) | 17 | (51.5) | 26 | (56.5) |
| high | 4 | (30.8) | 16 | (48.5) | 20 | (43.5) |
| Critical Comments | | | | | | |
| low | 9 | (69.2) | 22 | (66.7) | 31 | (67.4) |
| high | 4 | (30.8) | 11 | (33.3) | 15 | (32.6) |
| Hostility | | | | | | |
| low | 9 | (69.2) | 23 | (69.7) | 32 | (69.6) |
| high | 4 | (30.8) | 10 | (30.3) | 14 | (30.4) |
| EOI | | | | | | |
| low | 13 | (100) | 23 | (69.7) | 36 | (78.3) |
| high | 0 | | 10 | (30.3) | 10 | (21.7) |

Table 8.2 Proportions of carers who were High on more than one EE component

| | Male | | Female | | Total | |
|--------------------------|------|--------|--------|--------|-------|---------|
| | N | % | N | % | N | % |
| | 13 | (28.3) | 33 | (71.7) | 46 | (100) |
| CC and Hostility | | | | | | |
| no | 9 | (69.2) | 24 | (72.7) | 33 | (71.7) |
| yes | 4 | (30.1) | 9 | (27.3) | 13 | (28.3) |
| EOI and Hostility | | | | | | |
| no | 13 | (100) | 27 | (81.8) | 40 | (87.0) |
| yes | 0 | | 6 | (18.2) | 6 | (13.0) |
| CC and EOI | | | | | | |
| no | 13 | (100) | 28 | (84.8) | 41 | (89.1) |
| yes | 0 | | 5 | (15.2) | 5 | (10.9) |
| CC and Hostility and EOI | | | | | | |
| no | 13 | (100) | 28 | (84.8) | 41 | (89.1) |
| yes | 0 | | 5 | (15.2) | 5 | (10.9) |

Table 8.3 Proportions of carers who were High on only one EE component

| | Male | | Female | | Total | |
|--------------------|------|--------|--------|--------|-------|--------|
| | N | % | N | % | N | % |
| | 13 | (28.3) | 33 | (71.7) | 46 | (100) |
| <hr/> | | | | | | |
| Hostility only | | | | | | |
| no | 13 | (100) | 33 | (100) | 46 | (100) |
| yes | 0 | | 0 | | 0 | |
| Criticism only | | | | | | |
| no | 13 | (100) | 31 | (93.9) | 44 | (95.7) |
| yes | 0 | | 2 | (6.1) | 2 | (4.3) |
| EOI only | | | | | | |
| no | 13 | (100) | 29 | (87.9) | 42 | (91.3) |
| yes | 0 | | 4 | (12.1) | 4 | (8.7) |

(ii) Mean Scores of EE

Mean EE scores are shown in Table 8.4. It can be seen that the carer sample overall had a mean CC close to the High EE threshold (6.76) although the range was wide (0-32), as shown in Table 8.4. The other EE scale mean scores indicate that the sample overall was not Hostile, had Low EOI, showed some warmth and expressed few positive remarks. Women showed a significantly higher mean score for EOI (unequal t value = -3.4, d.f.=44, 95% C.I: -1.6, -0.4, p=0.002), but on CC and H the genders had similar means.

Table 8.4
 Carer Expressed Emotion Descriptive Characteristics: Mean EE Scores

| | Male (N=13) Mean (s.d.) | | Female (N=33) Mean (s.d.) | | Total (N=46) Mean (s.d.) | |
|---------|-------------------------------|--------|---------------------------------|--------|--------------------------------|--------|
| CC | 6.23 | (8.07) | 6.97 | (8.60) | 6.76 | (8.37) |
| (range) | | (0-23) | | (0-32) | | (0-32) |
| H | 0.69 | (1.18) | 0.61 | (1.06) | 0.63 | (1.08) |
| EOI | 1.00 | (0.71) | 2.00 | (1.25) | 1.72 | (1.2) |
| W | 2.31 | (1.03) | 2.12 | (1.22) | 2.17 | (1.16) |
| PR | 2.23 | (1.74) | 2.12 | (2.43) | 2.15 | (2.2) |
| (range) | | (0-5) | | (0-9) | | (0-9) |

(iii) Inter-Correlations between EE Components

The inter-correlations between the EE scales are shown in Table 8.5. Most of the inter-correlations are as expected. There was a significant high positive correlation between CC and H, a significant moderate positive correlation between PR and W, and significant moderate negative correlations between CC and W and between H and W. More surprising, was the low but significant positive correlation between EOI and H (this might be due to examining H as a continuous variable which is not usually done), and an absence of correlations between EOI and PR or W.

Table 8.5
Inter - Correlations between the EE components

| | | | | |
|-----|-----------|---------|---------|-----------|
| EOI | .28 | | | |
| | (0.06) | | | |
| PR | -.15 | -.02 | | |
| | (0.31) | (0.87) | | |
| W | -.59 | .05 | .45 | |
| | (<0.01)** | (0.73) | (0.01)* | |
| H | .76 | .30 | -.17 | -.45 |
| | (<0.01)** | (0.03)* | (0.25) | (<0.01)** |
| | CC | EOI | PR | W |

Spearman correlation statistic used for all correlations
Hostility coded as a continuous variable (0=0, 1=1, 2=1, 3=2)
* p significant at the 5% level
** p significant at the 1% level

8.3 SECTION TWO: UNIVARIATE ANALYSIS OF EE

This section reports the univariate testing between measures of EE and carer and illness-related variables. As noted earlier, it was also possible to employ one type of analysis to examine if the explanatory variables would differ in their association with High CC when High EOI was not present. Thus in this part of the analysis, the five carers who were high on CC and EOI were excluded and the tests were carried out using the 10 people who were High CC but not High EOI, comparing them to the Low EE group.

The appraisal-related variables' relationship to measures of EE, namely, burden, perceived social functioning, avoidant coping, distress and depression are shown first. This is followed by the patient illness-related variables relationship to measures of EE.

8.3.1 Burden and EE

The ECI total negative score can be thought of as subjective 'Burden' and this was analysed with EE (Table 8.6). Some areas of subjective burden might be associated with EE more than others (e.g. as in Smith et al., 1993). This is potentially important for both theoretical models of EE and clinical intervention (e.g. which facets of carer appraisal might be implicated, and therefore what to target in an intervention to lower burden). Domains of subjective burden have not previously been examined in relation to EE at the first episode. Therefore each of the eight burden sub-scales were tested with EE, which are described in the text (point ii) and the significant results are summarised in Table 8.7.

(i) Burden Total and EE

Burden total was significantly associated with overall High EE at the 5% level (Table 8.6). Burden total was also significantly associated with High CC and High EOI at the 1% level. However, High CC when High EOI was also not present was not significant.

Table 8.6: Burden Total: High EE component groups compared with the Low EE Group.

| | Mean | (s.d.) | D.F. | t | 95% C.I. | P |
|------------------------------------|-------|--------|------|------|----------------|--------|
| Low EE (N=26) | 63.6 | (36.9) | 44 | -2.4 | (-48.2, -4.0) | 0.02* |
| High EE (N=20) | 89.8 | (36.8) | | | | |
| Low EE (N=26) | 63.6 | (36.9) | 39 | -2.6 | (-55.0, -7.2) | 0.01* |
| High CC (N=15) | 94.7 | (35.6) | | | | |
| Low EE (N=26) | 63.6 | (36.9) | 28.0 | -2.6 | (-55.5, -7.1) | 0.01*^ |
| Hostility (N=14) | 94.3 | (35.0) | | | | |
| Low EE (N=26) | 63.6 | (36.9) | 34 | -2.6 | (-66.1, -7.8) | 0.01* |
| High EOI (N=10) | 100.6 | (42.8) | | | | |
| Low EE (N=26) | 63.6 | (36.9) | 34 | -1.2 | (-41.5, -38.9) | 0.25 |
| High CC but not High EOI (N=10) | 78.9 | (27.8) | | | | |

* p significant at the 1% level

^ unequal t-value used

(ii) Burden Sub-scales and EE

The eight burden sub-scales of the ECI are: need to backup, dependence, loss, difficult behaviours, stigma, effect on the family, problem with services, and negative symptoms. Seven of the eight burden sub-scales were significantly higher on at least one of the measures of High EE. Individual sub-scale findings are described below:

Difficult Behaviours: This was the only sub-scale to be significantly higher on all four main measures of High EE. EE overall was significant at the 1% level (t-value= -2.8, D.F. = 44, 95% C.I.: -11.5, -1.9, $p=0.007$). High CC was significant at the 0.01% level (t-value= -3.3, D.F. = 39, 95% C.I.: -13.6, -3.2, $p=0.002$). Hostility was also significant at the 0.1% level (unequal t-value= -3.8, D.F. = 27.7, 95% C.I.: -13.2, -3.1, $p=0.003$). High EOI was significant at the 1% level (unequal t-value= -2.6, D.F. = 15.5, 95% C.I.: -13.5, -1.7, $p=0.02$). In contrast, High CC without High EOI was not significant

Loss: Three measures of High EE were significantly higher than the Low EE comparison group, and a fourth was almost significant. Overall High EE was significant at the 5% level (t-value= -2.1, 95% C.I.: -7.2, 0.6, $p=0.05$ rounded up). Hostility was also significant at the 5% level (t-value= -2.2, D.F. = 38, 95% C.I.: -8.3, -0.4, $p=0.03$), as was High EOI (unequal t-value= -2.5, D.F. = 15.7, 95% C.I.: -10.2, -0.86, $p=0.02$). Although High CC was almost significant (t-value= -1.9, D.F. = 39, 95% C.I.: -7.8, 0.16, $p=0.06$), High CC without High EOI was not significant.

Problems with Services: Two measures of High EE were significantly higher than the Low EE comparison group, and two others were almost significant. Hostility was significant at the 5% level (t-value= -2.1, D.F. = 38, 95% C.I.: -9.1, -0.1, $p=0.05$ rounded up). High EOI was also significant at the 5% level (t-value= -2.4, D.F. = 34, 95% C.I.: -11.8, -0.97, $p=0.02$). High CC was almost significant (unequal t-value= -1.3, D.F. = 27.4, 95% C.I.: -8.8, 0.18, $p=0.06$), but High CC without High EOI was not significant. High EE overall showed a strong trend (t-value= -1.9, D.F. = 44, 95% C.I.: -8.3, 0.3, $p=0.07$).

Effect on the Family: One measure of High EE was significantly higher than the Low EE comparison group, and another was almost significant. Hostility was significant at the 5% level (t-value= -2.1, D.F. = 38, 95% C.I.: -7.8, 0.2, $p=0.05$ rounded up). High CC was almost significant (unequal t-value= -2.0, D.F. = 27.1, 95% C.I.: -7.7, -0.2, $p=0.05$, rounded down), but High CC without High EOI was not significant.

Dependence: This scale was significant at the 5% level with High EOI (t-value= -2.2 , D.F. = 34, 95% C.I.: -8.1, -0.4 , p=0.03), and showed a trend to be associated with High EE overall (t-value= -1.9, D.F. = 44 , 95% C.I.: -5.9, 0.2 , p=0.07).

Negative Symptoms: High CC displayed a trend towards significance (t-value= -1.9, D.F.=39, 95% C.I.: 07.76, 0.27, p=0.07), which was lost when High CC was tested without High EOI.

Stigma: None of the EE measures were significant.

Need to Backup: None of the EE measures were significant.

Table 8.7: Summary of Significant Burden Associations with EE

| | Overall High EE | High CC | H | High EOI | High CC not High EOI |
|------------------------|--------------------|------------|------|-------------|-------------------------|
| Burden total | Sig. | Sig. | Sig. | Sig. | --- |
| Difficult behaviours | Sig. | Sig. | Sig. | Sig. | --- |
| Loss | Sig. | --- | Sig. | Sig. | --- |
| Problems with services | --- | --- | Sig. | Sig. | --- |
| Effect on the family | --- | --- | Sig. | --- | --- |
| Dependence | --- | --- | --- | Sig. | --- |
| Negative symptoms | --- | --- | --- | --- | --- |
| Stigma | --- | --- | --- | --- | --- |
| Need to back-up | --- | --- | --- | --- | --- |

Sig. - p <5%% ---- - p> 5%

8.3.2 Avoidant Coping and EE

Avoidant coping was tested with the measures of EE. The avoidant coping total score was associated with all five measures of High EE at the 1% level.

Table 8.8
Avoidant Coping Total: High EE component groups compared with the Low EE Group.

| | Mean (s.d.) | D.F. | t | 95% C.I. | P |
|------------------------------------|-------------|------|------|----------------|-----------------------|
| Low EE (N=26) | 11.4 (4.0) | 32.7 | -3.8 | (-8.4, -2.3) | <0.01 ¹ ** |
| High EE (N=20) | 16.8 (5.7) | | | | |
| Low EE (N=26) | 11.4 (4.0) | 23.4 | -4.3 | (-10.0, -3.5) | <0.01 ¹ ** |
| High CC (N=15) | 18.1 (5.3) | | | | |
| Low EE (N=26) | 11.4 (4.0) | 38 | -4.9 | (-10.1., -4.2) | <0.01 ** |
| Hostility (N=14) | 18.5 (5.1) | | | | |
| Low EE (N=26) | 11.4 (4.0) | 34 | -3.9 | (-8.6, -1.6) | <0.01 ** |
| High EOI (N=10) | 16.5 (6.1) | | | | |
| Low EE (N=26) | 11.4 (4.0) | 34 | -3.4 | (-9.0, -2.3) | <0.01 ** |
| High CC but not High EOI (N=10) | 17.0 (5.5) | | | | |

* p significant at the 1% level ¹ unequal t-value

Individual avoidant coping styles and EE:

The avoidant coping measure comprises four scales of mental disengagement, behavioural disengagement, alcohol-drug disengagement and denial.

Behavioural disengagement: This scale was significantly associated with all five measures of High EE, four of which were below the 1% level [High EE overall: unequal t-value= -4.1, D.F. = 28, 95% C.I.: -2.2, -0.7, $p < 0.01$); (High CC: unequal t-value= -4.6, D.F. = 20, 95% C.I.: -2.6, -1.0, $p < 0.01$); (Hostility: unequal t-value= -4.9, D.F. = 18, 95% C.I.: -2.9, -1.1, $p = < 0.001$); High EOI: unequal t-value= -2.6, D.F. = 11, 95% C.I.: -2.6, -0.2, $p = 0.02$); (High CC not High EOI (t-value = 3.8, D.F. = 34, 95% C.I.: -2.3, -0.7, $p < 0.01$)]].

Mental disengagement: This scale was significantly associated with four measures of High EE at the 1% level and was almost significant at the 5% level with the fifth measure [(High EE overall: t-value= -2.8, D.F. = 44, 95% C.I.: -2.3, -0.4, $p < 0.01$); (High CC: t-value= -4.0, D.F. = 39, 95% C.I.: -2.9, -0.9, $p < 0.01$); (Hostility: t-value= -3.5, D.F. = 38, 95% C.I.: -2.8, -0.7, $p < 0.01$); High CC without High EOI: t-value = -2.7, D.F. = 34, 95% C.I.: -2.6, -0.4, $p = 0.01$); High EOI (t-value= -1.9, D.F. = 34, 95% C.I.: -2.4, -0.2, $p = 0.06$)]].

Alcohol-drug disengagement: This scale was significantly associated with five measures of High EE and showed a trend to be associated with a fifth [(High EE overall unequal t-value= -3.1, D.F. = 30, 95% C.I.: -3.1, -0.6, $p = 0.005$); (High CC unequal t-value= -3.0, D.F. = 20, 95% C.I.: -3.4, -0.6, $p = 0.008$); (Hostility t-value= -3.5, D.F. = 18, 95% C.I.: -4.0, -1.0, $p = 0.003$); (High EOI unequal t-value= -2.6, D.F. = 12, 95% C.I.: -4.0, -0.4, $p = 0.02$); (High CC without High EOI t-value = -2.4, D.F. = 34, 95% C.I.: -2.9, -0.2, $p < 0.08$)]].

Denial: This scale was not significantly associated with any measure of High EE, but showed a trend to be higher in the group who were High CC not High EOI (t-value= -1.8, D.F. = 34, 95% C.I.: -2.2, 0.4, p=0.08).

Table 8.9: Summary of significant avoidant coping associations with EE

| | Overall High EE | High CC | H | High EOI | High CC not High EOI |
|----------------------------|--------------------|------------|------|-------------|-------------------------|
| Avoidant total | Sig. | Sig. | Sig. | Sig. | Sig. |
| Behavioural disengagement | Sig. | Sig. | Sig. | Sig. | Sig. |
| Mental disengagement | Sig. | Sig. | Sig. | --- | Sig. |
| Alcohol-drug disengagement | Sig. | Sig. | Sig. | Sig. | --- |
| Denial | --- | --- | --- | --- | --- |

Sig. - p <5%% --- - p> 5%

8.3.3 Perceived Social Functioning and EE

Perceived Social Functioning was tested with EE using the overall SFS score and then with each of the seven sub-scales. An analysis of the sub-scales is important because some areas of social functioning may be related to EE more than others (e.g. Barowclough & Tarrier, 1990; Smith et al., 1993). Such information may also contribute to theoretical models of EE and guide clinical intervention. Areas of social functioning have not been previously examined in relation to EE at the first episode of psychosis.

(i) Total SFS Score and EE

Overall SFS score was significantly lower for the High CC and H groups, and High EOI showed a trend to be lower. High CC without High EOI was not significant.

Table 8.10
 Perceived Social Functioning Total: High EE component groups compared with the Low EE Group.

| | Mean (s.d.) | D.F. | t | 95% C.I. | P |
|------------------------------------|---------------|------|------|---------------|-------|
| Low EE (N=23) ^a | 131.47 (27.8) | 41 | 1.68 | (-3.2, 35.4) | 0.10 |
| High EE (N=20) | 115.40 (34.8) | | | | |
| Low EE (N=23) ^a | 131.47 (27.8) | 36 | 2.3 | (2.4, 40.3) | 0.03* |
| High CC (N=15) | 110.1 (28.8) | | | | |
| Low EE (N=23) ^a | 131.47 (27.8) | 35 | 2.3 | (2.4, 42.4) | 0.03* |
| Hostility (N=14) | 109.1 (31.1) | | | | |
| Low EE (N=23) ^a | 131.47 (27.8) | 31 | 1.8 | (-2.5, 48.7) | 0.08 |
| High EOI (N=10) | 108.3 (43.7) | | | | |
| Low EE (N=23) ^a | 131.47 (27.8) | 31 | 0.9 | -11.5, 29.4) | 0.38 |
| High CC but not High EOI (N=10) | 122.5 (22.9) | | | | |

* p significant at the 1% level¹ unequal t-value ^a Three SFS's not done in Low EE group.

(ii) Individual SFS Sub-scales and EE

The seven SFS sub-scales were tested with each EE measure:

Interpersonal Functioning: This scale was associated with all measures of High EE. EE overall was significant at the 1% level (t-value= 2.75, d.f.=41, 95% C.I.: 1.34, 8.78, $p<0.01$). High CC was significant at the 5% level (t-value= 3.2, d.f.=36, 95% C.I.: 2.3, 10.0, $p=0.03$). When High CC was tested without High EOI it retained its significant at the 5% level (t-value= 2.0, d.f.=31, 95% C.I.: -0.1, 8.7, $p=0.05$). Hostility was significant at the 0.1% level (t-value= 3.4, d.f.=35, 95% C.I.: 2.6, 10.3, $p=0.002$). High EOI was significant at the 5% level (t-value= 2.4, d.f.=31, 95% C.I.: 0.94, 10.9, $p=0.02$).

Independence Competence: This scale was associated only with High EOI (unequal t-value= 2., d.f.=11.0, 95% C.I.: 1.4, 8.7, $p=0.05$).

Withdrawal: This scale was associated only with High EOI (t-value= 23, d.f.=31, 95% C.I.: 0.33, 5.5, $p=0.03$).

Recreation: Two trends were observed with this scale and measures of High EE. They were High CC (t-value= 1.8, d.f.=36, 95% C.I.: -0.54, 7.9, $p=0.09$), and Hostility (t-value= 1.7, d.f.=35, 95% C.I.: -0.6, 8.2, $p=0.09$). High CC lost its trend when it was tested without High EOI being also present.

Prosocial activities: This scale showed only one trend, which was with Hostility (t-value= 1.8, d.f.=35, 95% C.I.: -0.8, 11.4, $p=0.09$).

Independence performance: This scale was not associated with any EE measure.

Employment: This scale was not associated with any EE measure.

Table 8.11: Summary of significant social functioning associations with EE

| | Overall High EE | High CC | H | High EOI | High CC not High EOI |
|---------------------------|--------------------|------------|------|-------------|-------------------------|
| Total SFS score | --- | Sig. | Sig. | --- | --- |
| Interpersonal functioning | Sig. | Sig. | Sig. | Sig. | Sig. |
| Independence competence | --- | --- | --- | Sig. | --- |
| Withdrawal | --- | --- | --- | Sig. | --- |
| Recreation | --- | --- | --- | --- | --- |
| Prosocial activities | --- | --- | --- | --- | --- |
| Independence performance | --- | --- | --- | --- | --- |
| Employment | --- | --- | --- | --- | --- |

8.3.4 Depression and Distress Scores and EE

The BDI total score, GHQ total score and the four GHQ subscales were not associated with any measure of High EE.

8.3.5 Patient Illness-Related Characteristics and EE

Diagnosis, illness length, age at onset, total severity of symptoms, and severity of symptom dimensions (neurotic, depressive, manic and psychotic) were all not significant when tested with the five measures of High EE. With reference to the 70 SCAN item groups, using the 5% chance criteria, there should be 17 item groups which are significantly associated with at least one measure of High EE (5% of 350). Only 11 such associations were found, which is less than chance. Further, all but two are undermined by a very low number of observations. These were delusions of control, which were present

in 6/10 patients with High EOI carers, and emotional turmoil, which was present in 8/10 patients with High EOI carers. However, overall, there was an overwhelming lack of association between illness-related variables and the measures of EE. Therefore, there was no credible statistical basis for including these two symptom results in the EOI regression analysis.

Table 8.12

Summary table of significant carer appraisal associations with measures of High EE

| | Overall High EE | High CC | H | High EOI | High CC not High EOI |
|------------------------------|--------------------|------------|------|-------------|-------------------------|
| <u>Burden</u> total | Sig. | Sig. | Sig. | Sig. | --- |
| Difficult behaviours | Sig. | Sig. | Sig. | Sig. | --- |
| Loss | Sig. | --- | Sig. | Sig. | --- |
| Problems with services | --- | --- | Sig. | Sig. | --- |
| Effect on the family | --- | --- | Sig. | --- | --- |
| Dependence | --- | --- | --- | Sig. | --- |
| <u>Avoidant coping</u> total | Sig. | Sig. | Sig. | Sig. | Sig. |
| Behavioural disengagement | Sig. | Sig. | Sig. | Sig. | Sig. |
| Mental disengagement | Sig. | Sig. | Sig. | --- | Sig. |
| Alcohol-drug disengagement | Sig. | Sig. | Sig. | Sig. | --- |
| <u>SFS</u> total | --- | Sig. | Sig. | --- | --- |
| Interpersonal functioning | Sig. | Sig. | Sig. | Sig. | Sig. |
| Independence competence | --- | --- | --- | Sig. | --- |
| Withdrawal | --- | --- | --- | Sig. | --- |

8.3.6 Which EE Component(s) contributed to the significant univariate results?

It was noted in Chapter 4 that very few studies, in the context of likely or definite High EE sample co-morbidity, attempted to tease out which component(s) might be responsible for their significant results. The present study employed both descriptive totals of different EE combinations, and partial correlations of CC and EOI used as continuous variables, to assess which component(s) were contributing to the significant differences between High and Low carers. Theoretical accounts of EE in the literature (e.g. Patterson et al., 2000; Kavanagh, 1992) have usually focused on a distinction between High CC and High EOI. The EE groupings in the present study permitted an examination of whether High CC or High EOI or both were contributing to the variance. However, it should be noted that H appeared so often with High CC (13/15 High CC were also H) that differences between High CC v High EOI carers may be due to Hostility or some combination of High CC with Hostility. Also, since H is not a continuous variable, it was obviously not possible to use the type of partial correlation approach employed with CC and EOI. It should also be noted that the High EOI alone group was very small (N=5).

The descriptive totals of each of the carer appraisal variables were compared with respect to High CC not High EOI, High EOI not High CC and High CC plus High EOI. The results are shown in Table 8.13. Though base numbers are small, it can be seen that when there is High component co-morbidity, the scores are much higher (or lower in the case of perceived social ability). The second approach to judging which component(s) might be responsible for the significant associations was to use partial correlations (Table 8.14). Burden, avoidant coping and perceived social functioning were tested with CC and EOI as continuous variables, controlling for one another. The results indicated that when one component was controlled the correlation co-efficients and p-value of the other does not increase, as would be expected if just one component were responsible for the association. Instead, all nine correlation co-efficients and p-values are reduced when CC or EOI is controlled for the other. This suggests that both components were, to some extent, contributing to the variance.

Table 8.13

Carer appraisal scores for High CC and High EOI alone and together

| | High CC not High EOI (N=10) | High EOI not High CC (N=5) | High CC plus High EOI (N=5) |
|--------------------|-----------------------------------|----------------------------------|-----------------------------------|
| Burden | 78 | 67 | 126 |
| Avoidant Coping | 17 | 10 | 20 |
| Social Functioning | 122 | 145 | 85 |

Table 8.14

Carer appraisal components’ partial correlation scores and p-values when CC and EOI are, and are not, controlled for each other

| | CC | CC Controlling for EOI | EOI | EOI controlling for CC |
|--------------------|---------------|------------------------------|--------------|------------------------------|
| Burden | .31 (p=0.03) | .26 (p=0.09) | .27 (p=0.06) | .25 (p=0.10) |
| Avoidant Coping | .51 (p=0.01) | .46 (p=0.02) | .23 (p=0.11) | .12 p=0.42) |
| Social Functioning | -.36 (p=0.01) | -0.32 (p=0.03) | -.19 (p=0.2) | -.11 (p=0.45) |

Taking the descriptive results and partial correlations together, it appears that the reduced number of significant associations found in the univariate analysis in the High CC group was not due to High EOI explaining the bulk of the variance. Instead, it appears that *both* High CC and High EOI were contributing something to the significant carer appraisal associations. So the loss of significant associations in the High CC without High EOI analysis was probably due to reduced group size and so loss of statistical power.

8.4 EE MULTIVARIATE ANALYSIS

Multivariate analyses were conducted on the EE overall classification and the other three measures of High EE (High CC, H, High EOI, High CC not High EOI) in order to establish which explanatory variables would be the strongest predictors of each measure. Following guidelines specified in the Method section, Logistic Regressions (LR's) using the likelihood ratio statistic were carried out for each type of EE. To re-cap, this approach removes 'nuisance' variables and so reveals which variables link to EE independently, indicating the simplest and most powerful model. The criterion for entry into the LR was that the variable was significant at the 5% level in the univariate analysis.

The stepwise forward method of LR was chosen. This method finds the variable that has the strongest association with the dependent variable and then continues adding variables until the addition of another variable is not significant at the 5% level. Since the total score and sub-scale of a variable can not be entered at the same time, variables were entered in *Chunks*, so that the model would potentially include only the simplest and most generalisable variables. For example, burden total was entered before burden sub-scales and avoidant coping was entered before the sub-scales of behavioural disengagement, mental disengagement, substance use, and denial.

The multivariate results are presented below for each High EE analysis. Specified for each analysis are the variables which were entered into the logistic regression, the order in which they were entered and which variables were chosen for the model. It will be recalled

that there was no credible basis for testing whether carer appraisal variables would be stronger independent predictors of EE than illness-related characteristics.

8.4.1 Logistic Regression of Overall EE

The variables used for the Overall EE logistic regression were entered in the following chunks and order: Chunk 1) Burden total, avoidant coping. Chunk 2) Difficult behaviours, loss, behavioural disengagement, mental disengagement, alcohol-drug disengagement, interpersonal functioning. The LR indicated that EE Overall was best predicted by avoidant coping (Table 8.15)

Table 8.15
EE Overall Multivariate Results

| | OR | -2 Log LR | P |
|-----------------|-----|--------------|---------|
| Avoidant Coping | 1.2 | 10.9 | 0.005** |

Likelihood ratio statistic used

** p significant at the 1% level

8.4.2 Logistic Regression of CC

Variables were entered into the High CC Logistic Regression in the following chunks and order: Chunk 1) Burden total, avoidant coping total, SFS total. Chunk 2) Difficult behaviours, behavioural disengagement, mental disengagement, alcohol-drug disengagement, interpersonal functioning. CC status is best predicted by a model containing avoidant coping (p=0.001), as shown in Table 8.16.

Table 8.16

CC Multivariate Results

| | OR | -2 Log LR | P |
|-----------------|-----|--------------|------------|
| Avoidant Coping | 1.3 | 14.4 | <0.0001 ** |

Likelihood ratio statistic used

** p significant at the 1% level

8.4.3 Logistic Regression of Hostility

Variables were entered into the Hostility Logistic Regression in the following chunks and order: Chunk 1) Burden total, avoidant coping total, SFS total. Chunk 2) Difficult behaviours, loss, problems with services, effect on the family, behavioural disengagement, mental disengagement, alcohol-drug disengagement, interpersonal functioning. The variable that best predicts Hostility status is avoidant coping (Table 8.17).

Table 8.17

Hostility Multivariate Results

| | OR | 2 Log LR | P |
|-----------------|-----|-------------|----------|
| Avoidant Coping | 4.2 | 5.8 | 0.003 ** |

Likelihood ratio statistic used

** p significant at the 1% level

8.4.4 Logistic Regression of EOI

The variables entered for the EOI logistic regression were entered in the following chunks and order: Chunk 1) Burden total, avoidant coping total. Chunk 2) Difficult behaviours, loss, problems with services, dependence, behavioural disengagement, alcohol-drug disengagement, interpersonal functioning, independence competence, withdrawal. EOI status is best predicted by avoidant coping (Table 8.18).

Table 8.18
EOI Multivariate Results

| | -2 Log | | |
|-----------------|--------|-----|-------|
| | OR | LR | P |
| Avoidant coping | 1.2 | 6.3 | 0.02* |

* p significant at the 5% level
likelihood ratio statistic used

8.4.5 Logistic Regression of High CC not High EOI

The variables entered for the EOI logistic regression were entered in the following chunks and order: Chunk 1) avoidant coping total. Chunk 2) Behavioural disengagement, mental disengagement, interpersonal functioning (Table 8.19).

Table 8.19
High CC not High EOI Multivariate Results

| | -2 Log | | |
|-----------------|--------|-----|---------|
| | OR | LR | P |
| Avoidant coping | 1.3 | 8.0 | 0.000** |

* p significant at the 1% level
likelihood ratio statistic used

8.4.6 The Ability of Avoidant Coping to Predict EE Status

Although avoidant coping was the best predictor for all the High EE measures, it varied in its ability to classify correctly carers as Low EE as compared to High CC, H, High EOI, and High CC not High EOI. The variable was much better at predicting Low EE, correctly classifying 82% (versus High EE), 87% (versus High CC), 87% (versus H), 96% (versus High EOI), and 96% (High CC not High EOI). Avoidant coping correctly classified a much lower proportion of High EE carers: 70% (High EE), 66% (High CC), 64% (H), 40% (High EOI), and 40% (High CC not High EOI). Avoidant coping therefore increases the prediction of High EE to a certain extent for the overall High EE classification, High CC and H groups (chance would be 50%), but is worse than chance when it comes to High EOI and High CC not High EOI. One reason why avoidant coping was only modestly predictive of some High EE measures, and poorly predictive of other measures, might be because the relationship it had with both CC and EOI was less-than-linear. The real predictive power of avoidant coping lies with correctly detecting Low EE carers. A frequency breakdown of avoidant coping in the High versus Low EE group revealed that Low EE carers as a whole group used each avoidant strategy, on average, less than rarely; whereas High EE carers as a whole group used them more than rarely.

8.5 SUMMARY OF CHAPTER 8

Section one described the levels and distribution of carer EE and the inter-relationship between the EE components in the sample of 46 carers. Nearly half the sample were High EE, a fifth to a quarter were High EE by more than one measure, and correlations between EE components were generally as expected. There was a low refusal rate, very little missing data, and inter-rater reliability was acceptable.

Section two described the univariate relationship between the variables for which hypotheses were made and the measures of EE. High EE overall, High CC, Hostility, High EOI and High CC without High EOI were all compared with the Low EE group. The carer appraisal-related variables of burden, avoidant coping and perception of social functioning all showed some significant associations with High EE. Within each of these variables, various differences emerged between sub-scales and different measures of High EE. When High CC was tested without the people who were also High EOI, the burden and perceived social functioning totals lost their significant association with High EE, although the association with avoidant coping remained significant. The other carer appraisal-related variables of the BDI total score, GHQ total score and the four GHQ sub-scales were not associated with any measure of High EE. The illness-related characteristics were overwhelmingly not significantly associated with High EE. In order to judge which EE component(s) were most likely to be responsible for the significant associations observed, descriptive calculations and partial correlations were carried out comparing CC/H with EOI. The results suggested that both CC/H and EOI were contributing to the differences between High EE measures and the Low EE comparison group.

Section three described the multivariate analysis of EE. A stepwise forward logistic regression was carried out for each measure of High EE. Avoidant coping was the strongest independent predictor of EE status. The variable increased the correct classification of Low EE carers considerably above the (50%) chance level. Avoidant coping also improved the classification of High EE overall, High CC and H carers, but

performed worse than chance for High EOI and High CC not High EOI. This may have been due to a less-than-linear relationship between criticism and EOI with avoidant coping.

Chapter 9:

Discussion of the Overall Descriptive Results

9.1 INTRODUCTION

The socio-demographic and illness-related characteristics of first episode psychosis samples are influenced by a wide range of factors. No other study has used the present project's mixture of inclusion criteria which spans the carer, life-event onset, and life event-delusional theme studies. This means that it is not possible to compare the sample characteristics with an equivalent study. Despite this, the gender split, age, onset age and illness length of the study are worthy of comment because they help to place the characteristics of the present sample in the context of the relevant literature. They also assist in assessing both the representativeness of the present sample and the validity of some of the results.

9.2 DISCUSSION OF THE OVERALL SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE SAMPLE

9.2.1 Gender Proportions

The gender-split in first episode psychosis studies appears to be highly variable, excluding studies which specifically targeted groups which would be likely to contain a higher proportion of one of the genders (e.g. Knobler et al., 2000, army recruits: 73% male; Beighley et al., 1992, air force recruits: 100% male; Tan & Ang, 2001, 100% male). Early reviews of the gender-split in first episode studies on schizophrenia concluded that males were heavily over-represented (e.g. Riecher, 1989; Iacono & Beiser 1992). Iacono and Beiser (1992) found 70-75% males (depending on the schizophrenia definition employed), and some more recent studies have found similar high proportions of males (e.g. Barnes, Hutton, Chapman, Mutsatsa, Puri & Joyce, 2000: 79%; Ericson, 1998: 78%; Drake et al., 2000: 70%). However, the very large (N=1379) WHO study on first episode schizophrenia found nearly equal gender proportions (745 male, 54%, Jablensky et al.,

1986, p.916). The stressful life event sub-study sample of the WHO project included 386 patients, and found 51% males (198/386; arithmetic undertaken by the present author of data presented in Day et al., 1987, Tables 6.1 and 6.2 p.153 and 155 respectively). Strikingly, this is also the exact gender proportion reported in the Camberwell study by Castle et al. which included 486 patients, and exactly the same as a study by Bottlender, Straub, & Moller (2000, p.147) which included 998 first episode schizophrenia patients. Therefore, for schizophrenia, it seems that smaller first episode samples often identify a clear over-representation of males, but the very large studies identify only slightly more males.

A key influence on the gender split is the width of the age inclusion criteria. Many first episode studies on schizophrenia have found that males are over-represented in younger age bands, whereas females tend to be over-represented in older age groups (Leung & Chue, 2000, and Jablensky, 2000, review the issue). The present study's sample included 65.5% of people with schizophrenia and had a wide age band inclusion criteria (16-65), finding an overall gender split of 62% males. Although the gender split of the patients that refused to participate in the EE study was not recorded, 4/5 of those who refused to participate in the life event study were male. This suggests that the overall gender split of refusals might have slightly lowered the male proportion. The male proportion of 62% found in the present study is higher than in the large schizophrenia studies but seems fairly typical of smaller schizophrenia studies.

The gender split for first episode samples which include other psychoses also varies in the literature. There appears to be only one epidemiological study which recruited the full range of functional psychoses but which did not involve skewed sampling. This was the study by Schwartz et al., (2000) which involved people aged 15–60. Their initial report (Bromet et al., 1992) involving 188 patients had found a equal gender split. Their recent report (i.e. Schwartz, et al., 2000) involved 547 patients and found 56.5% were males. A large first episode psychosis study by McGorry et al. (1998) involved 509 patients and found 65.8% males, but it excluded ages above 45 for the first 6/9 years of recruitment,

then also excluded people over 30 for the remaining three years of recruitment. Other much smaller studies of first episode psychosis have found, as with first episode schizophrenia studies, a tendency for an excess of males which varies in magnitude, as illustrated by examples from recent studies in Table 9.1. The table supports the view that the present finding of 62% male appears to be neither exceptionally high nor low for a first episode psychosis study. If the upper age limit of the present study's inclusion criteria had been lower, this would probably have led to a higher proportion of males.

Table 9.1: Examples of gender proportions in recent first episode psychosis studies.

| Authors | % Male |
|------------------------------|--------|
| Das et al. (2001) | 40 |
| Greenfield et al. (1994) | 50 |
| Cole et al. (1995) | 53 |
| Tohen et al. (1992) | 54 |
| Cohen et al. (2000) | 55 |
| Schwartz et al. (2000) | 57 |
| Lehtinen et al. (2000) | 57 |
| Aguilar et al. (1997) | 58 |
| Sipos et al. (2001) | 59 |
| Halford et al. (1999) | 60 |
| Cantwell et al. (1999) | 60 |
| Strakowski et al. (1998) | 60 |
| Verdoux et al. (2001) | 62 |
| Patterson et al. (2000) | 62 |
| Raune et al. (present study) | 62 |
| Larsen et al. (2000a) | 65 |
| McGorry et al. (1998) | 66 |
| Dalkin et al. (1994) | 66 |
| Gupta et al. (1997) | 66 |
| Krstev et al. (1999) | 81 |

Note. Proportions are rounded to the nearest percentage.

9.2.2 Sample Age

The mean age of the present study sample was 31.0 (median age 28). There appears to be only one epidemiological study in the literature which included the broad range of functional psychoses and yet did not involve inclusion criteria which would heavily skew the age of the sample. This, again, was the large study by Schwartz et al. (2000), which had an age inclusion criteria similar to the present study (ages 15-60). The initial report, involving 188 patients, found a median age of 31, and the recent report (i.e. Schwartz et al., 2000) involving 547 patients found a median of 28 years, identical to the present study's median age. On the other hand, many other recent first episode psychosis samples (usually much smaller than Schwartz's sample) have found a lower mean sample age, as illustrated by Table 9.2. Although this shows that some other studies have found a similar or higher sample age, the present study's sample age does appear higher than typical first episode psychosis samples. To explain this, it should be pointed out that unlike many first episode psychosis samples (e.g. McGorry, et al., 1998; Patterson, et al., 2000; Larsen, et al., 2000b), the sample of the present study was not recruited as part of an early intervention service. Such services often pro-actively target young people and also exclude older people (e.g. as in McGorry et al., 1998). Table 9.2 shows that Larsen's sample ages before (Larsen et al., 2000a, p. 4) compared to after (Larsen et al. 2000b, p. 160) the inception of an early intervention service dropped by nearly five years (28.4 v 23.6). Other first episode psychosis studies which were not part of an early intervention service exclude people above a certain age for other reasons. For example, the study by Knobler et al. (2000) included only military recruits, who were all between the ages of 18-22; and Menezes and Milovan (2000) review many studies which included only adolescents. In the present study nine patients (15.5%, four men, five women) had late onsets (after age 40), including two (3.4%) with very late onsets (after age 60). Unlike patients in the present study, early intervention studies also often attempt to reduce illness length. For example, Larsen et al. (2000b) reported that their early intervention service reduced duration of untreated psychosis by an average of 97 weeks compared to their previous non-early intervention service. The present study included five patients (8.6%) who had onsets more than two years ago, including three men (5.1%) whose onset was more than four years

ago. In summary, the mean age of the present sample is higher than typical similar studies, and there are clear reasons for this. However, since the median age is identical to that of the most representative study in the literature, the sample is probably not particularly skewed in terms of age.

Table 9.2:
Examples of mean sample age in recent first episode psychosis studies.

| First Episode Psychosis Study | Mean Sample Age |
|------------------------------------|-----------------|
| Krstev et al. (1999) ^a | 21.6 |
| Larsen et al. (2000b) ^a | 23.6 |
| Gupta et al. (1997) | 24.0 |
| McGorry et al. (1998) ^a | 24.4 |
| Erikson et al. (1998) | 24.4 |
| Tennakoon et al. (2000) | 25 |
| Aguilar et al. (1997) | 26.6 |
| Strakowski et al. (1998) | 26 |
| Sipos et al. (2001) | (median) 28 |
| Schwartz et al. (2000) | (median) 28 |
| Larsen et al. (2000a) | 28.4 |
| Lehtinen et al. (2000) | 28.7 |
| Halford et al. (1999) | 30.8 |
| Cantwell et al. (1999) | 31 |
| Raune et al. (present study) | 31.1 |
| Verdoux et al. (2001) | 31.6 |
| Greenfield et al. (1994) | 32.3 |
| Tohen et al. (1992) | 32.8 |

Note. Some studies only report figure to two significant figures

^a Sample recruited in an early intervention service.

9.3 DISCUSSION OF THE OVERALL ILLNESS-RELATED CHARACTERISTICS OF THE SAMPLE

9.3.1 Onset Age

The study by Schwartz et al. (2000), and also their earlier report (Bromet et al., 1992), unfortunately do not state the onset age of their overall sample, and it is not possible to calculate it from the data presented in the papers. There appears, therefore, to be no definitive and unskewed epidemiological study on first episode psychosis which would provide a benchmark to interpret the mean onset age of the present sample (which was 30 years). Some large studies on schizophrenia have found an onset age slightly lower than the present study. For example, Hafner and Heider (1997) found the first positive symptom appeared at the mean age of 29. As already mentioned, the Camberwell study on schizophrenia (Castle et al. 1998 p.29) used a similar definition, and found an onset age of 36, much higher than the present study. However, compared to other studies which included other psychoses - and which also used a definition of onset which emphasised positive symptoms - the present study's mean onset age appears higher than typically found. For example, Larsen et al. (2000b) and McGorry et al. (1998) found onset ages of 26.3 and 23.9 years, respectively. This may be because (unlike these and many other studies), the present sample was not recruited from an early intervention service which emphasised the detection of young people. Indeed, as noted, 15.5% of the sample had late onsets (after age 40), consistent with the fact that late-life psychosis is a well-established and relatively common phenomenon (e.g. Castle et al. 1998). Other first episode psychosis studies that were not part of an early intervention service, which also found a lower mean onset age than the present study, often had an upper age limit inclusion criteria which was lower than the present study's age of 65 (e.g. Craig et al., 2000: 60; Strakowski et al., 1998: 45; Gupta, Andreasen, Arndt, Flaum, Hubbard, & Ziebell, 1997: 35; Knobler et al., 2000: 22). The finding that males had onsets earlier than females by 3.5 years is consistent with reviews of the issue (e.g. Leung & Chue, 2000).

9.3.2 Illness Length

Illness length in the present study was defined as the time between the emergence of the first positive symptom and the SCAN interview. The illness length findings are probably comparable to studies which have measured duration of untreated psychosis because patients were interviewed as soon as possible after admission (usually shortly after anti-psychotic medication had begun). The epidemiological study by Schwartz et al. (2000) of first episode psychosis unfortunately did not report illness length in terms of an overall sample mean or median as this would have assisted with the interpretation of the present study's finding of a mean of 40.0 weeks. The mean illness length of the present study appears longer than first episode psychosis samples which were recruited as part of an early intervention service (e.g. McGorry et al., 1998: 26.4 weeks; Krstev et al., (1999): 13.9 weeks; Patterson et al., 2000: five weeks). However, many other first episode psychosis studies which did not recruit as part of an early intervention service have also found a long duration of untreated psychosis (e.g. Loebel et al., 1992: 51.9 weeks; Larsen et al., (2000a): 114 weeks). Keshavan and Schooler (1992), in their review of first episode psychosis characterisation, found duration of untreated psychosis to be on average between one and two years. They comment that people can live for a long time in society with severe positive symptoms of mental illness, without receiving treatment. The present study's illness length was similar to a separate study carried out in the same catchment area (44 weeks, Tennakoon et al., 2000).

The longer male duration of untreated psychosis is consistent with other studies (e.g. Loebel et al. 1992). The relationship between the illness length summary statistics (mean 40.0 weeks, standard deviation 57.8 weeks and median 18.0 weeks) is typical of first episode psychosis samples, and suggests the presence of outliers (Birchwood, 2000, p.45). Nine-percent (5/58) had an illness length of more than two years, one of whom had been continuously ill and cared for by his (High EOI) mother for over five years. Although it is not possible to be certain that this small group of people had been continually in their first episode of psychosis, 4/5 had carers who were questioned closely about the possibility of recovery then relapse during the period between illness onset and the patient's admission.

The issue would in any case only have possible implications for the EE study - not the life event studies - because all the illness lengths in the latter were less than 52 weeks.

A small number of patients (4/58, 7%) were still delusional at interview. Three of these patients participated in both the life event-onset (3/41, 7%) and event-delusional theme (3/40, 7%) studies. It is possible that some other patients still held delusional beliefs which they kept secret. The possibility that patients recalled events in a way consistent with their delusional system was dealt with by rigorous application of the conservative LEDS rating system. Any doubtful events that could not be confirmed by a carer were not included in the analysis.

9.3.3 Diagnosis of Schizophrenia

There is considerable variation in the proportion of patients in first episode psychosis samples who receive a diagnosis of schizophrenia. The large epidemiological study by Schwartz et al. (2000) found 22.4% when 188 patients were recruited, and then found 34.6% when 547 patients had been assessed. The present study found a much higher proportion, with 65.5% of the sample classified by SCAN as having a schizophrenia disorder, while many other smaller studies have found a lower proportion (e.g. Halford, Steindl, Varghese & Schweitzer, 1999: 30.7%; Rabiner, James, Wegner & Kane, 1986: 46%; Beiser et al., 1994: 51.4%; Craig et al., 1998: 54%; Knobler, et al., 2000: 61.1%). Yet many others have found a higher proportion (e.g. Sipos, Harrison, Gunnell, Amin, & Singh, 2001: 67.5%; Krstev, Jackson, & Maude, 1999: 68%; Dalkin, Murphy, Glazebrook, Medley, & Harrison, 1994: 70%; Larsen et al., 2000a: 74%). Finally, the large study by McGorry et al. (1998) found an almost identical proportion to the present study, at 64%. The present study sample's proportion of patients with a schizophrenia diagnosis therefore appears to be within previously found parameters.

9.4 LIFE EVENT SAMPLE: DISCUSSION OF THE SOCIO-DEMOGRAPHIC AND ILLNESS-RELATED CHARACTERISTICS

There is only one other first episode psychosis study on life events in the literature which included the full range of functional psychoses (Das et al., 2001), and the few studies which are closest in design to the present one differ in important ways. Such differences include inclusion criteria relating to gender (e.g. the military studies contained mainly men), and event type (e.g. many studies sampled by recruiting people who had experienced a particular event, such as marriage). Other differences include patients who are first admission rather than first episode (e.g. Jacobs & Meyers, 1976), diagnosis (most studies included only schizophrenia patients), length of period questioned about before onset (which influences illness length e.g. most studies went back only three months before onset rather than the present one's twelve months). This means that comparing the present study's socio-demographic and illness-related characteristics to such studies is of doubtful validity.

Despite this, the mean sample age is still worthy of comment in relation to the life event study because it could, in theory, have implications for the validity of the results. A recent review on the issue of earlier onset leading to a poorer outcome, concluded that neither the adolescent or adult literature demonstrates an association robust enough to have been demonstrated as valid (Menezes & Milovan, 2000). However, if the hypothesis was correct, then when a sample's mean age is much higher than is typically found, this could mean that the patients included had a less severe illness and / or a lower biological loading for psychosis; and so the participants might be more likely than typical samples to have had a psychosis which was stress-related. Thus the results of the present study would be more likely than other studies to find a significant life event association. As discussed, the present study's onset and sample ages were lower than in some first episode schizophrenia/psychosis studies, but appeared higher than found by typical first episode studies. However there appear to be clear reasons for this, and the median sample age of the present study was in fact identical to the only large-scale epidemiological study in which sample age was not obviously skewed in a major way (Schwartz et al., 2000). With

reference specifically to the life event sample median age, it is in fact lower than the study by Schwartz et al., (26.9 v 28). This suggests that the sample was not biased towards older groups and that the sample age does not imply a less severely ill or vulnerable patient group.

9.5 EXPRESSED EMOTION SAMPLE: DISCUSSION OF THE SOCIO-DEMOGRAPHIC AND ILLNESS-RELATED CHARACTERISTICS

The socio-demographic and illness-related characteristics of the EE patient sample are very similar to the overall sample, and issues about onset age, sample age, gender, diagnosis and illness length were discussed earlier. Although these variables have no clear relationship to EE, in order to put the sample characteristics of the present EE study into the context of the EE literature, it is possible to compare some variables with those found in other studies. However, it should be borne in mind that most other studies only included patients with schizophrenia and usually included some patients who were non-first episode psychosis.

On gender, the present EE study had a proportion of 58% males, which appears to be in the middle of the range compared to other similar studies (e.g. Barrelet et al., 1990: 37%; Stirling et al., 1993: 46%; Hugulet et al., 1995: 48%; Macmillan et al., 1986: 58%; Patterson et al., 2000: 61.5%; Mintz et al., 1989: 88%). The mean patient age in the present sample was clearly higher than in previous studies (e.g. Linszen et al., 1996: 20; Mintz et al., 1989: 22; Stirling et al., 1993: 23; Patterson et al., 2000: 23; Barralet et al., 1990: 24; Macmillan et al., 1986: 25). The sample had a later illness-onset than was typical. This may have been influenced by a number of factors such as a higher upper age inclusion criteria limit (e.g. the upper age limit in the Stirling et al. study was 50; in the present one it was age 65), the inclusion of psychoses other than schizophrenia (most studies), and the fact that recruitment was not part of an early intervention service (e.g. as in Patterson et al. 2000). Concerning illness length, the present study found a mean illness length of 10.9 months, similar to Mintz (10 months) and Linszen (10.1 months), but longer than some others (e.g. Macmillan et al. 4.8 months; Stirling et al. 5.5 months;

Patterson et al. 5 weeks). The socio-demographic characteristics of the carers appear broadly similar to those in other studies on early psychosis.

9.6 SUMMARY OF CHAPTER 9

In order to place the findings of the present study in the context of the first episode psychosis literature, this chapter has discussed some of the sample's socio-demographic and illness-related characteristics. It was noted, first, that no other study in the literature provides an exact comparison. The gender split of the sample was 62% male. The proportion is higher than the large-scale studies on schizophrenia and yet tends to be lower than typical smaller studies on first episode psychosis. However, the proportion is similar to smaller studies on schizophrenia and the one large age-unskewed study of first episode psychosis. The gender split therefore does not appear to be unrepresentative of people with first episode psychosis who make contact with hospital services. The median sample age (28) was identical to the one large-scale unskewed study on first episode psychosis so also appears to be representative of first episode psychosis patients. On the other hand, the sample age was higher than typical first episode, probably mainly due to the upper age limit inclusion criteria and the fact that people were not recruited as part of an early intervention service. The onset age (mean of 30 years) was not dissimilar to large schizophrenia studies but appears higher than in typical first episode psychosis studies. This, again, is probably mainly due to the upper age inclusion criteria and the absence of an early intervention service.

It was argued that the 9% of people who had very long illness lengths were probably still first episode patients. It was also argued that the possible problem of patients recalling events in a way consistent with their delusional systems was probably dealt with effectively using the LEDS methodology. The proportion of people in the sample with a schizophrenia-related diagnosis was within the parameters found by other studies. Regarding the life event study sub-sample, it was shown that the sample age and onset age did not support the theoretical possibility that the sample was biased towards patients who may have been more likely to show a stress-induced psychosis. With respect to the sub-

sample of patients in the EE study, it was noted that the descriptive characteristics were similar to other studies. The carers also appeared to have broadly similar characteristics to other studies on early psychosis.

Chapter 10:

Discussion of Stressful Life Events and the Onset of Psychosis and Delusional Theme

10.1 INTRODUCTION

This chapter discusses the findings of the stressful life event-psychosis onset study and then examines the event-delusional theme study.

10.2 STRESSFUL LIFE EVENT – PSYCHOSIS ONSET STUDY

The main aim was to test a possible aetiological role for events in the first episode of psychosis by examining if events clustered in the period nearer to onset. This was the first study to examine if events would cluster in the three months before onset compared to the preceding nine. In doing so, the study attempted to address unanswered questions about event timing, severity, independence and type. The study also attempted to replicate previous findings that events cluster in the final three weeks before onset. The ‘gold standard’ life event instrument, the LEDS, was employed for the first time at the first episode of psychosis. Before discussing the findings, it is necessary to look at the limitations of the study.

10.2.1 Study Limitations

(i) Absence of a Control Group

The most basic limitation of this study is the absence of a control group. However, testing for event clustering is one of the several types of evidence that can be used to argue for an aetiological role for events, even though it is not, in itself, sufficient evidence to conclude that a causal link exists.

(ii) Representativeness of the Sample

Recruitment to the study was not epidemiological, which limits the generalisability of the results to the whole population of people with first episode psychosis. However, not all patients had a hospital admission and the catchment area included Croydon, which potentially allowed a greater diversity of socio-economic characteristics in the sample. Patients had to have dateable onsets within one year before interview, which reduces the applicability of the

results to people with more insidious onsets. To meet the study inclusion criteria, patients were initially required to have one of the four psychosis themes (reference, grandiose, depressive or persecutory) in a delusion or voice. The voice inclusion criteria was for a sub-study which is not part of this thesis. In practice, only one person had a voice without co-morbid delusions and so was included in the event study but not the delusion study. However, the results are only representative of patients who have at least one of the delusional themes, not of patients whose symptoms have other psychotic contents.

(iii) Observer Bias

All the SCAN and LEDS assessments were carried out by the same person, which might have biased the ratings of life events in line with the themes identified by the SCAN. However, about a third of cases were presented in full to an independent panel chaired by Tirril Harris, and many other single events were also presented. The ratings were deemed sufficiently accurate. In addition, rating of the LEDS audio-tapes occurred several months after interviewing which meant themes were not easily recalled by the researcher.

(iv) Data Input Errors and Transformation Errors

In order to avoid data input errors, the data file was scanned for rogue values and in each case outliers were checked. A considerable number of ‘intermediary’ variables (329) were computed in order to make it possible to apply suitable statistical tests. Each test was checked for calculation errors by manually checking a small number of cases.

(v) Recall Inaccuracies

a) Forgetting of Events

Patients were questioned about the year before onset. This means that the maximum recall period was two years and people might not have recalled earlier events. However, Graphs 7.3 and 7.5 show that the number of independent threat events and the number of independent threat events of marked/moderate severity in the year before onset actually decreases between periods 4, 3 and 2, before rising in period 1 in the three months before onset. This argues against the view that people forgot events further back in time.

b) Effort After Meaning

People with first episodes of psychosis might recall events as being closer to onset than they actually were and as being more severe than they were. In this way, the 'blame' for the psychosis locates itself externally to the person (an 'effort after meaning' effect). To counter the first possibility all events were related to 'anchoring points' in the person's recent history. To counter the second possibility, the LEDS rates all events contextually, ignoring the patient's subjective view of how severe the event was.

d) Delusional Recall

This was discussed in Chapter 9 and is further examined in section 10.5.3.

(vi) Event Severity

There are many ways to examine the issue of event severity. The present study explores the issue by repeating the severity analyses using only events of marked/moderate severity. This study has not attempted to statistically analyse the issue exhaustively e.g. by then also testing events of 'some' threat as a separate category. This is because the issue is not the primary focus of the study and no a priori hypothesis is made. In this context, further tests risk type I errors.

10.3 WAS THERE A LINK BETWEEN EVENTS AND THE FIRST EPISODE OF PSYCHOSIS?

The main aim of the present study was to test for an aetiological role for events in the first episode of psychosis by examining the extent to which they clustered before onset. Along with discussion of the results on this issue, are findings relating to event timing, severity, independence and type. Before discussing these it is helpful to place the event rates of the present study in the context of the literature on other first episode/admission studies, but it should be noted that no other study used the LEDS, so the results are not perfectly comparable.

10.3.1 Event Prevalence in the Present Study Compared to other First Episode/Admission Studies

(i) One Year Before Onset

The mean stressful event rate for one year (4.51) is higher than the two other comparable studies (3.2, Jacobs & Myers, 1976; 1.05, Das et al., 2001). Jacobs and Meyers do not present the exact figure for number of independent events but do state that 40.3% of cases had at least one, which is lower than the present study result of 75.6%. Das et al., do not report on the issue of event independence. A higher figure compared to that in the two other previous studies is not surprising, because both used a checklist, whereas the present one used a semi-structured interview that was likely to be more thorough.

(ii) Twelve Weeks Before Onset

The mean total event rate in the final 12 weeks of this study (1.39) is in between other first episode psychosis studies: Brown and Birley (1968) 1.74; Al-Khani et al. (1986) 1.23; Day et al. (1987) aggregating the 5 developed countries, N=136, 1.64).

The event rate for independent events in the final 12 weeks (0.80) is also in between other published data sets: Brown and Birley (1968): 1.02; Day et al. (1987), aggregating the 5 developed countries: 0.96; Al-Khani et al. (1986): 0.76. The proportion of people with at least one event in the final 12 weeks (63.4%) is somewhat lower than the value from the biggest study (Day et al. (1987), figure for 5 developed countries: 79.6%). Similarly, the proportion of people who experienced at least one independent event in the final 12 weeks (43.9%) is somewhat lower than that of Day et al. (1987) (aggregated 5 developed countries, 57.6%). The independent event rate in the final 12 weeks falls slightly below the figure of Day et al. (1987) for estimated upper and lower range for life event prevalence before the first episode (upper 65%, lower 50%).

(iii) Three Weeks Before Onset

The proportion of people who had at least one independent event in the final 3 weeks (19.5%), was lower than in the two other studies for which figures are available (Brown & Birley, (1968), 46%; Day et al. (1987), aggregating the 5 developed countries, 32.8%). This might be

due to the fact that the present study used a more elaborate classification of independence than these two studies.

In summary, the event rates reported here are comparable to those in other first episode studies, except that the event rate in the final three weeks seems appreciably lower.

10.3.2 Did Events Cluster Before the First Episode of Psychosis?

In order to test for an aetiological role of events on first episode psychosis, the study examined the extent to which events clustered in the three weeks or three months before onset. It was found that the total number of threat events was almost significantly clustered, and the number of independent threat events of marked/moderate severity showed a strong trend to cluster in the three months before onset compared to the preceding nine months. Further, significantly more people had experienced at least one independent event of marked/moderate severity in the final three months compared to the previous nine months. There are no other studies that have assessed for this pattern over one year before the onset of psychosis (first episode or relapse). However, the pattern is consistent with Bebbington et al. (1993) whose sample was mainly (64%) of non-first episode patients who found that event clustering did begin several months before relapse. The clustering of events in the last three months is also consistent with the 'peaking' statistic of Steinburg and Durrell (1968). They found a 'dramatic excess' of onsets of schizophrenia in the first month of military training, which declined gradually thereafter. This study has therefore demonstrated for the first time at a statistically significant level that first episode psychosis patients might be influenced by events which are more distal in time than the previously found three weeks before onset (e.g. Day et al. 1987). The results are therefore supportive of a possible stress-incubation effect, operating at least three months before onset.

Although the present study did not find any significant clustering in the last three *weeks* compared to the preceding nine, the prevalence was higher in all four combined groups in those final three weeks (marked/moderate/some threat with possibly independent/independent; marked/moderate/some threat with independent only; marked/moderate threat with possibly independent/independent; and marked/moderate with independent only). The pattern in the final three weeks is therefore broadly similar to several others studies. For example, Day et al.

(1987), found clustering of independent events in all six centres where such an analysis was possible.

10.3.3. What Role did Severity and Independence Play at Onset?

The study has been the first to investigate the issue of event severity at the first episode, an issue that is also under-researched in terms of relapse. The findings are not open to a simple interpretation as they were inconsistent with regard to the two levels of event independence. With reference to the *number* of events, which are marked/moderate/some threat there was an almost significant clustering. However, this trend was lost when the analysis was confined to independent events. In contrast, events which were of marked/moderate severity were not significant with independent/possibly independent events; but when the analysis was confined to independent events only, a trend appeared. Similarly, when those who experienced at least one event were examined, the clustering was only significant for independent events. These inconsistencies are probably the result of inadequate power.

The results therefore do not provide clear-cut support for the sensitisation hypothesis, which would predict that only events with appreciable threat would provoke a first episode. The issue touches on the debate about the relative predictiveness of the total number of events added together versus the proportion of people who had at least one more severe event (Brown & Harris, 1989). The results of the present study might in future be compared with a group of exclusively relapsing patients, in order to see if either of these methods of analysis indicates a greater severity at onset as compared to relapse.

10.3.4 What Further Role did Independence Play at Onset?

The possibility that events did play a role in onset is further strengthened by the fact that events commonly occurred which were rated as independent. The prevalence of those who had at least one independent event was 75.6% over one year, 43.9% over 12 weeks and 19.5% over the last 3 weeks. The fact that independent events of marked/moderate severity cluster significantly while those of the same severity level that were independent/possibly independent do not, supports a key component of the model of psychotic symptoms proposed by Garety et al. (2001). They argue that psychosis patients' decision to attribute their symptoms to an external source is a defining moment in the development of a psychotic disorder. Objectively

independent events might encourage people to make such attributions for what happens to them more generally, including perhaps, the symptoms of their psychotic illness.

10.3.5 Was there An Excess of Events Compared to the Normal Population?

Another characteristic about events before the onset of psychosis that increases the likelihood that they are exerting an aetiological effect is whether or not events occur with a greater prevalence than in the normal population. The mean independent event rate over one year (2.34 per person) unfortunately cannot be compared to the other two studies to use a one year assessment period. This is because the authors either do not state the relevant figure (Jacobs & Myers, 1976) or do not report independence at all (Das et al., 2001). The rate in the present study over the final twelve weeks (0.80) is only slightly higher than Brown and Birley's (1968) 325 control group (0.71). Yet when a different statistic is applied - the proportion of people experiencing at least one independent event - a different picture emerges. This statistic has an advantage over mean numbers of events because it is not vulnerable to being skewed by a few outlier individuals with a large number of events. Using this statistic, the present study's prevalence of people in the year before onset (75.6%) appears considerably larger than that of Jacobs and Myers (1976) control group (29%), although it is considerably more than their rate for schizophrenia patients (40.3%), too. The number of people experiencing at least one independent event of marked/moderate severity in the final twelve weeks (46.3%) also seems considerably larger than the control group used by Brown and Birley (1968), in which 14.2% of controls experienced an event; and that of Bebbington et al. (1993), in which 7.2% experienced an independent event. Yet the finding in the present study is reasonably close to the 36.8% quoted for psychosis in the study of Bebbington et al. (1993), although lower than Brown and Birley's finding of 60%. So the results of the present study do seem to indicate that the first episode patients were more likely to have experienced an independent event in the months before onset compared to people in the general population. However, there are two qualifications to this. First, control group data from Bebbington et al. (1993) was obtained in 1978-1979, and event rates might have changed over the last 20 years, although this is very unlikely to account for such a major increase. Secondly, a more valid comparison is to compare people with psychosis and controls who have been matched on a case by case basis, to reduce the possibility that differences were due to different socio-demographic or other characteristics.

10.3.6 Did Particular Events Play a Special Role in Triggering Onset?

As discussed in Chapter 2, the search for a particular type of event that triggers psychosis has been relatively fruitless. The main supporting evidence is for events characterised by intrusiveness (Harris, 1987; Harris, 1991; Day, 1989). The present study did find that intrusive events were common. For example, nearly three-quarters (73.2%) of the sample had at least one event in the year before onset, and over a quarter (26.8%) in the final twelve weeks. However, intrusiveness seems to be no more common than the other types of event characteristics (loss, danger, self-esteem, humiliation). When graphed into four periods over the year before onset, intrusive events were observably higher in the three months before onset compared with the other three periods. However, a similar pattern was found for loss, self-esteem and humiliating events. The rate of independent intrusive events over 12 weeks (26.8%) and three weeks (9.8%) seems to be considerably more than the rate for the normal population quoted by Harris (1987, 3% and 1%.) The concept of intrusiveness fits conceptually with many types of event studies of psychosis (i.e. military training, military invasion, High EE, arranged marriage and sexual abuse). However, the proportion of people in the study who reported at least one severe independent loss and danger event over a one year period also appears considerably higher than that of a published normal control group (loss 10% V 34% and danger 12% V 41%, Finlay-Jones & Brown, 1981), although the authors studied only women. Thus the present study provides a tentative suggestion that intrusive events might play a special role in psychosis onset, however a suitable normal control group (which includes males as well as females) who are rated on other stress dimensions would be essential to test the specificity of intrusiveness properly.

10.4 SUMMARY OF THE THEORETICAL IMPLICATIONS OF THE EVENT-ONSET STUDY

This study has extended what is known about the association between prior stressful events and the first episode of psychosis in a number of ways. First, it has been found that events cluster further back in time before the first episode than had previously been established. This supports the validity of applying stress vulnerability frameworks developed for relapse to the first onset. It also suggests the possibility of stress-incubation. The event clustering, together with the event prevalence, independence, severity and rate compared to the normal population, argues that events may play an aetiological role at the first episode. The results did not provide

clear evidence for sensitisation, but there are other and more thorough ways of testing the issue. The combination of higher event severity with event independence may be important when considering the initial onset. It is possible that independent events may contribute to the external attribution for symptoms that is thought to be fundamental in psychosis. New information was presented on the wide range of types of events that befall patients in the year before their first episode of psychosis. There was tentative support that intrusive events might play an important role however the issue has not been examined exhaustively or with a suitable control group.

10.5 WERE THE STRESSFUL EVENTS LINKED TO PSYCHOTIC THEMES?

This study is the first study to test a stressful life event-delusional theme hypothesis in a group design using an a priori hypothesis. The instrument used has greater evidence of validity than those used in previous studies. Most cognitive work on the causation of delusional themes has been cross-sectional (Garety & Freeman, 1999) and therefore demonstrates association rather than cause. One strength of the psychosocial evidence presented in this thesis is that the stress *preceded* the themes, so there is a greater chance they are causal (rather than merely correlated). Further, the inclusion of an exclusively first episode sample permits the testing of influences which might be related to initial causation (onset) and not just the re-emergence of the symptoms (relapse). The first episode design also removes the clouding influence of a range of variables which are inherent in non-first episode studies which might cloud the theme results. The hypothesis chosen for testing the issue was that intrusive events would predict the development, specifically, of persecutory delusions. Before discussing the findings, it is helpful to discuss some threats to the validity of the study.

10.5.1 Possible Threats to Validity

(i) Low Power

Part of the rationale for testing the psychosocial stress-delusion hypothesis with persecutory delusions as the dependent variable, is that they are commonly found in first episode hospital samples (e.g. Castle et al, 1998). However, as it turned out, so few patients lacked this delusional theme (12.8%) that the study had reduced power to test the hypothesis.

(ii) Generaliseability of Results

All patients in the present study came from a hospital, so the results may be less generaliseable to people with persecutory delusions who never come into contact with hospital services.

(iii) Theme Co-Morbidity at the First Episode

An advantage of using the intrusive-persecutory hypothesis to test a role for psychosocial stress on delusions, was that intrusive events were predicted to link only with a persecutory theme (as discussed in Chapter 3). The high co-morbidity of delusional themes found in the present sample justified using this type of ‘theme-specific’ hypothesis, as the persecutory theme commonly existed in association with both grandiose (33%) and depressive (28%) themes. Though these two co-morbid themes do not represent a threat to the validity of any intrusive-persecutory association, they could affect the specificity of any link. Therefore, tests were carried out to examine if intrusive events would be associated with these two themes. There were *no* significant associations or even trends between the experience of intrusive events and the presence of these themes. Since only two participants did not have a reference theme it was not feasible to test the reference theme in this way. It was therefore possible that any association between intrusive events and a persecutory theme might arise spuriously because of the link between themes of persecution and reference. However, all five people who lacked a persecutory theme did have a reference theme, so intrusive events are unlikely to predict the development of reference delusions with any sort of specificity. A related issue concerns the possibility that whilst the non-persecutory group obviously did not have persecutory delusions, they might have had persecutory voice contents. This might theoretically cloud any differences between the persecutory and non-persecutory groups and risk a type II error. However, only one person in the non-persecutory group heard a voice, and the content was not persecutory, so this theoretical problem was not an issue in the present sample.

(iv) The Theoretical Possibility of Theme Evolution and the Theoretical Inter-Relationship between Themes at the First Episode

It is theoretically possible that patients involved in the theme study might have had different delusional themes at the time of the SCAN interview to that at the onset of the illness. This might have obscured any association between prior events and the themes reported at the time

of interview. There is no published information on the inter-relationship between themes. In this study persecutory and reference themes were present together in 85% of patients. A qualitative observation is that some patients seemed to report initial suspiciousness about being watched or followed without, at that point, holding the belief that harm was directed against them. So persecutory themes may sometimes develop from reference themes. Thirty-three percent of patients had both grandiose and persecutory themes. Therefore another obvious possibility is that patients who exhibit grandiose delusions might also develop persecutory delusions after being ridiculed and rejected. When one theme develops after another, it is currently unknown whether this has any implications for the original theme. For example, in the present study, co-morbid depressive and grandiose themes were rare (8%) so these themes might be antagonistic to one another. There are few data on the issue, but one study that looked at themes in successive relapses found that they tended to re-appear rather than change across episodes (Jorgensen & Jensen, 1994).

The period which the SCAN interview covers confines itself to the last 28 days if the patient is still in episode, or if the episode has only just remitted. For patients whose episode was more than the 'notional month' ago, patients are asked about the time of greatest psychotic symptom severity. Both situations leave open the possibility that psychotic themes might have developed and indeed subsequently disappeared outside the periods the patient was asked about. However, the mean illness length was only 17 weeks, and the 'notional month' which the SCAN asks about extends to about six weeks. Therefore, if theme evolution did occur, it would have done so during the space of only about nine weeks. In addition, the SCAN items are so unusual, and the questioning and cross-referencing so thorough, that it seems unlikely that patients would not have reported all four of the themes if they had experienced them. Moreover, the case notes usually contained interview information with the patient and their relatives spanning the course of the illness. Every set of case notes was examined thoroughly for evidence of themes, and all patients were probed further about any themes which were implied by the case notes which the patient did not report during the SCAN interview. EE interviews with carers provided another back-up source of information on the issue in about 70% of cases. Therefore, while it is theoretically possible that theme evolution confounded the study's results, there is no evidence that it actually did, and the short illness lengths combined with the thoroughness of the assessment make it unlikely.

(v) Event Co-Trauma at the First Episode

People in the sample commonly experienced a wide range of events in the year before onset. People who had experienced intrusive events had only rarely (5%) not experienced at least one of the other event types. Intrusive event co-trauma with other types of event occurred in high proportions of the sample (danger 61%, loss 51%, self-esteem 63%, humiliation 63%). However, an advantage of using the intrusive event hypothesis was that no other stress dimension is hypothesised to influence a persecutory theme. Although intrusive events themselves may often carry additional dimensions of stress (as discussed in Chapter 2), the literature provides no evidential basis for arguing that any of the other event dimensions would confound the intrusive-persecutory association. Despite this, all the other event types were tested with a persecutory theme, for two reasons: first, because such testing would show if the intrusive-persecutory link was specific to intrusive rather than other types of events (danger, humiliation, loss, self-esteem); secondly, because of the theoretical possibility that the association between intrusive events and persecutory theme might be due to some other stress dimension. Results showed that there were no significant or even trend results between the other event types and a persecutory theme.

(vi) The Possibility of Events after Onset Influencing themes

The study sought to establish causal connections by asking patients about events before onset, not after. However, if the hypothesis that psychosocial stress influences delusional themes were true, then it implies that events occurring *after* onset might also have led to the development of some delusional themes. This would camouflage any prior event-theme connection, and remains a theoretical possibility. A more thorough approach than that of the present study might be to assess events up to interview, and then statistically control for events occurring after onset but before interview.

(vii) Mood Congruent Recall

The possibility of mood-congruent recall was tested by examining the event rates for grandiose, depressive and persecutory delusional groups. If a mood congruence effect was operating to influence the results, people with depressive delusions would recall more unpleasant events and people with grandiose delusions less unpleasant ones. In fact, post hoc testing indicated that people with grandiose delusions recalled a slightly higher number of events (4.35) than the

depressive delusion group (4.18), with the persecutory delusion group in between (4.32). These findings argue against a mood-congruent recall bias affecting the results.

10.5.2 Intrusive Events and Persecutory Theme

The hypothesis was that intrusive events would predict the development of persecutory delusions at first episode psychosis. Of the thirty-nine patients, 34 reported persecutory delusions and five did not. Background support for the hypothesis came from the event-onset study, which, as discussed, found evidence consistent with events exerting an aetiological role at the first episode.

As noted earlier, the small proportion of patients who did not have a persecutory delusional theme reduced the ability to detect differences between groups and increased the danger of a type II statistical error. However, there were two interesting findings. There was a trend ($p=0.09$) for there to be a higher number of independent intrusive events of marked/moderate severity in the persecutory delusion group and the finding that none of the non-persecutory group had experienced such an event compared with 41% of the persecutory group. When the other types of events were tested with persecutory theme using proportions of people who had at least one event, there was always at least one person in the non-persecutory group who had experienced one of the tested events. For intrusive events which were independent and of marked/moderate severity, this was never the case. The largest descriptive difference between the groups appears to be when it comes to the proportion of people who have experienced independent intrusive events. This suggests that there could be something extra that an event contributes to a persecutory theme when it is obviously not caused by the patient.

Although the intrusive-persecutory result is not statistically significant, it is nonetheless scientifically intriguing and clinically interesting. Table 10.1 lists the content of one independent intrusive event of marked/moderate severity for each of the 14/34 people in the persecutory delusion group (some patients experienced more than one, so only the most serious is shown for each person). It can be seen that many are, on common-sense grounds, potentially ‘paranoia inducing’ (Harris, 1991).

Table 10.1

Independent intrusive events of marked/moderate severity experienced by the 14/34 people with persecutory delusions, but NOT experienced by any of the non-persecutory group

| Event | Patient Code No. |
|--|------------------|
| Patient discovers nephew, aged 15, is being given crack cocaine | (0004) |
| Patient mugged by man with knife | (0006) |
| Patient infected with sexually transmitted disease | (0009) |
| Patient is physically assaulted by husband | (0010) |
| Patient attends Crown Court and is questioned about someone attempting to rape her | (0014) |
| Patient mugged by gang on train, one has a knife | (0018) |
| Patient punched and kicked by three men at a train station | (0035) |
| Patient’s brother is arrested by police, long prison sentence likely | (0037) |
| Patient’s flat is burgled for the second time | (0038) |
| Patient testifies in court against three men, they threaten future violence | (0040) |
| Patient is verbally abused, punched and kicked by her husband | (0041) |
| Patient given a council flat on ‘rough’ estate. Gang on estate break his jaw | (0052) |
| Patient’s husband holds bread knife to her throat and threatens to kill her | (0058) |
| Patient mugged at knife point | (0065) |

Where a person had more than one independent intrusive event of marked/moderate severity. the most severe event is shown.

10.5.3 Was the Association between Intrusive Events and Persecutory Delusions Due to Inaccurate Delusional Recall?

For 10/14 of the intrusive events of marked/moderate severity, carers were able to confirm that they actually happened and also when they happened (in four cases there was no carer). The intrusive event-persecutory delusion link was also tested again, this time leaving out the four people who had no-one to confirm their event(s). This reduced the power of the tests, but the p-value only drops by 0.02. Similarly, the proportion of people who experienced at least one such event only drops by 5%, still leaving more than one in three with such an event compared to none of the non-persecutory delusion group. These post hoc tests therefore argue against any substantial bias from delusional recall.

10.5.4 The Association between Intrusive Events and Persecutory Theme in Perspective

The results show that whilst an intrusive event might, in some cases, be sufficient for the development of persecutory delusions, such an event is not necessary. Twenty-six percent of people with a persecutory delusion did not experience any intrusive events. Themes which are less ego-related might show even less association with psychosocial stress.

10.6 THEORETICAL IMPLICATIONS OF THE DELUSION RESULTS

The results provide some initial support for Harris's (1987) post hoc but empirically tested theory of the 'paranoia inducing event'. Similarly, they support Lemert's (1962) conclusion that many patients with paranoia may be basing their delusions on genuine experiences where they were the victim. It is also consistent with the study of Harrow et al., (1988) who found that 70% of delusions stemmed from worries that were present before delusions. The finding is also consistent with studies that found a high rate of paranoia in immigrants (e.g. Murphy, 1955). The results are compatible with Frith's model of schizophrenia (Frith, 1992) and of persecutory delusions in particular (e.g. Frith & Corcoran, 1996). It is possible that stressful events of an intrusive type - such as those found in this study (burglary, mugging, verbal or physical assault etc.) - alter fundamental schemas that a person uses to judge the motives of other people. In other words, intrusive events might influence the 'biased theory of mind default setting' (Corcoran, 1999) which seems to operate in paranoia. Similarly, the results are consistent with a role for independent intrusive events influencing the way psychotic symptoms are appraised. For example, when voices are appraised as uncontrollable and malevolent

(Morrison, 2001). The results are supportive of a role for affect in the development of delusions (e.g. Garety and Hemsley, 1994) and persecutory delusions in particular (e.g. Blackwood et al., 2001). The results also suggest that independent events might contribute to the external attributional style found repeatedly in persecutory delusions (e.g. Garety & Freeman, 1999; Blackwood et al., 2001), which is also a fundamental part of the model proposed by Garety et al. (2001) to explain the positive symptoms of psychosis. The fact that most of the intrusive events were perpetrated by other people might contribute to the external *specific* attributional style found in persecutory delusions (Kinderman & Bentall, 1997). The results also tend to argue against the cognitive modelling of delusions in isolation from the social context in which they occur (Birchwood, 1999). Within a stress-vulnerability framework, the results tend to support the view that stress might not just trigger symptoms per se, but might also influence the content of at least one type of delusion. Finally, the post hoc specificity testing included examining a role for self-esteem events in persecutory delusions. None of the results were significant or showed any trends, suggesting self-esteem events were not causal to persecutory delusions. These results are consistent with the one other study that examined the temporal relationship between self-esteem and persecutory delusions (Freeman et al., 1998), as well as the most recent review of persecutory delusions (Blackwood et al., 2001).

10.7 POSSIBLE CLINICAL IMPLICATIONS OF THE EVENT-ONSET AND EVENT-THEME STUDIES

The results of the stressful event studies in this thesis have some potential implications for early psychosocial intervention for psychosis. These implications are organised into the three categories of assessment, intervention, and specific interventions for delusions.

10.7.1 Assessment

(i) Social Context of Psychosis

The results support the view that psychosis needs to be understood within the context of a person's biographical history and current social circumstances (Fowler, 2000). Psychosocial stress will often be an antecedent factor in first onset. In assessing a person who has first episode psychosis, results here suggest that about two-thirds of people may have experienced a stressful life event in the 12 weeks immediately before onset and nearly half of these will have

suffered an event of marked/moderate severity. Added to this must be events that occur after onset but before assessment.

(ii) Affective Disturbance

The prevalence of events before onset suggests that, in addition to psychotic symptoms, emotional disturbance is likely to be common. Birchwood et al. (1993) argue that people with psychosis are affected by stressful events just as the general population is. It may be that, as in the normal population, the type of stressful event before onset will partly predict the type of affective disturbance present in the first episode, for example, loss events and depression, and danger events and anxiety. Additionally, the presence of danger events might partly predict which patients will experience most delusional distress. This is because danger events link with worry and anxiety (e.g. Finlay-Jones & Brown 1981) and worry has been linked to delusional distress (Freeman & Garety, 1999).

(iii) Post-Traumatic Stress Features

In non-epidemiological sampled designs, some studies have found a high prevalence of post-traumatic stress disorder (PTSD) after psychotic relapse (Morrison et al., 1999; Mueser et al., 1998; McGorry et al., 1991). Psychosis itself may be capable of provoking a PTSD reaction. In addition to this, in the current sample there was a high prevalence of events of marked/moderate severity in the year before onset (82.9% in the last 12 months and 46.3% in the final three months). First episode patients should therefore probably be screened for symptoms of post-traumatic stress disorder.

10.7.2 General Intervention for Psychosis

(i) The Fundamental External Attribution

This thesis found that many first episode patients will have recently experienced at least one very unpleasant event over which they had no control. Early therapeutic work might therefore discuss with the patient how fateful events might lead someone into believing that what happened to them is the work of some external force or power. This may help to reduce the fundamental attribution error in psychosis that Garety et al. (2001) propose.

(ii) Environmental Manipulation and Recovery

The prevalence and pattern of stressful life events before psychosis, and the fact that perhaps half of the people with persecutory delusions may have recently experienced an unpleasant uncontrollable intrusive event, underlines the importance of the social environment for the person recovering from psychosis. It thus supports the use of early intervention using a standard stress management component to reduce positive symptomatology and speed recovery via affect reduction, (e.g. Drury et al., 1996). Keeping the number of stressful life events to a minimum would seem an important clinical aim.

(iii) Enhancing Engagement

Making links between psychosis and the person's experience improves the power of the clinical formulation and is likely to be more acceptable to patients than the explanation that they are simply 'ill'. Thus engagement in the treatment process, which Jackson et al. (1995) comments can be particularly difficult for first episode patients, might be facilitated.

10.7.3 Delusion Intervention

Discussing with patients the possibility that their (delusional) persecutory beliefs may sometimes be based on actual recent experiences might be normalising for them (Kingdon & Turkington, 1991). Therefore early therapeutic work would seem important to ensure that less evidence apparently confirming a delusional belief has time to accumulate, and that contrary evidence can be found early on. This could take the form of both milieu therapy and specific reality testing experiences, within the context of a CBT for psychosis approach (e.g. Fowler et al. 1995). Events may have exaggerated fundamental underlying beliefs, so CBT may need to be aimed at this schema level. People may be helped to understand that they may be over-generalising the implications of recent events. For people with first episode persecutory delusions, the evidence here is that nearly half (41.3%) will have experienced a recent uncontrollable intrusive event. A cognitive re-assessment of the implications of this event might help reduce catastrophic and categorical thinking. Relapse-prevention might focus on planning how the person with persecutory delusions will cope with future ('paranoia inducing') intrusive events. Therapy will need to disentangle which events were independent of the patient, which were caused by the patient (but not the illness) and what might be due to the patient's illness. This might help the new psychosis patient with a more realistic interpretation of the role of

both external stress and the role of personal vulnerabilities in the onset of persecutory delusions.

10.8 FUTURE RESEARCH DIRECTIONS FOR PSYCHOSOCIAL STRESS AND THE ONSET OF PSYCHOSIS

The time has come for a much more sophisticated approach to understanding psychosocial stress in psychosis, including at the first episode. There is an extensive array of methods and techniques in the psychosocial stress and depression literature which await application in the field of psychosis, especially at the first episode. Rather than examining single stressors, it would be better to take a multiple approach, encompassing stressful events, types of stressful events, difficulties, types of difficulties and expressed emotion. Vulnerability factors (e.g. social isolation, low self-esteem) could also be examined. The possible role of protective factors such as warmth, positive remarks and positive events are also completely unexplored in psychosis onset. Many statistical approaches are now available which help to tease out the relative role of each of the stressors, vulnerability markers and protective factors (e.g. Surtees, 1989; Frank et al., 1996). In this way, the understanding of psychosocial stress at the first episode will move away from single broad stressors to an understanding of increasingly specific psychosocial stress-illness relationships. This is likely to identify therapeutic priorities for intervention.

10.9 FUTURE RESEARCH DIRECTIONS FOR PSYCHOSOCIAL STRESS AND DELUSIONAL THEMES:

The association between intrusive events and persecutory delusional themes requires re-testing with a larger non-persecutory comparison group. It should also provide some encouragement to test other possible stress dimensions with other delusional themes. However, hypotheses should ideally have both event-specificity and theme-specificity. For example, the association between intrusive events and a persecutory theme was not tested with respect to the 'poor me - bad me' persecutory distinction (Trower & Chadwick, 1995). In the present study, it is possible that the 14/34 people who did experience an independent intrusive event of marked/moderate severity might have shown 'poor me paranoia' and the other 20 people 'bad me' persecutory worries. Prospective longitudinal research would be useful to examine whether different dimensions of persecutory delusions change after intrusive events, as well as whether different forms of intrusion link with different persecutory themes. This would also

address the question of whether stress-theme links are obscured by themes evolving over time. As with studies on stress-onset per se, assessing for other forms of intrusiveness such as critical comments and difficulties which are intrusive, might also identify clearer relationships. Studies on psychosocial stress might benefit from assessing for events up to interview, so that they can be controlled statistically. Overall, the time has come to place a greater emphasis in research on the role of the wide range of psychosocial stressors that might potentially influence delusional themes, and to do this in a more specific and multivariate manner.

10.10 SUMMARY OF CHAPTER 10

This chapter discussed the results of the stressful event-onset study and the stressful event-delusion study. The event-onset study aimed to test an aetiological role for events at the first episode by examining if they clustered nearer to onset, compared with further away. No first-episode study had previously tested for a clustering comparing the final three months with the preceding nine months. The main limitation of the study was the absence of a control group. Forty-one patients were included and, consistent with the hypothesis, independent events of marked/moderate severity did cluster in the final three months before onset compared to the preceding nine months. The study was unable to replicate previous findings of a clustering in the final three weeks. However, the significant event clustering, high prevalence, high prevalence of independent events, and event rate compared to the general population argue that events may play an aetiological role at the first episode. Independent events might contribute to the external attribution error that appears to be fundamental in psychosis. The event delusion study aimed to test a role for psychosocial stress on the development of delusional theme. The hypothesis was that intrusive events would predict the development of persecutory delusions. The main strength of the study was the fact that it tested a causal influence before the emergence of the theme, and used an a priori hypothesis in a group design. The main limitation was low power. Thirty-nine patients, of which 34 had persecutory delusions and five did not, were compared with respect to the rate of intrusive events before onset. The results were not significant but they were scientifically and clinically suggestive. Theoretical implications of the two studies were discussed with reference to stress-vulnerability frameworks of psychosis and models of delusions. Clinical implications related to early stress-management in general and CBT for delusions in particular. Future research directions for the field of psychosocial stress and psychosis were identified.

Chapter 11:

Discussion of Expressed Emotion at the First Episode of Psychosis

11.1 INTRODUCTION

The main aim of the EE study was to test the validity of a carer appraisal model of EE, and a secondary aim was to examine if carers appraisal was a stronger independent predictor of EE than patient illness-related factors. The main hypotheses were that, consistent with a stress-appraisal model of High EE, carers would be more burdened, use more avoidant coping, perceive more patient social functioning deficits, and report more distress and depression than Low EE carers. This study has been the first to test these factors with EE using a sample of exclusively first episode psychosis patients and carers. Unlike most previous studies, the present one has related each explanatory variable to all four measures of High EE (Overall, High CC, Hostility and High EOI). Attempts have also been made to tease out the independent influence of EE components to the independent variables, as well as to identify the strongest independent predictors of EE using multivariate statistics. The main findings of the present study replicated previous studies' findings concerning carer appraisal variables, extending them to the first episode of psychosis. The study was unable to replicate any of the illness-related factors which had sometimes been found to be associated with EE.

This discussion is divided into four parts. The first part discusses the methodological limitations of the EE study. The second part relates the results, wherever possible, to previous (usually non-first episode) work in the area. The third part attempts to combine the results and relate them to a theoretical model of EE. This part also discusses implications for stress-vulnerability frameworks of psychosis and future directions into research of EE. The fourth and final part discusses implications for early clinical intervention.

11.2 PART 1: METHODOLOGICAL LIMITATIONS OF THE EE STUDY

11.2.1 EE Study Design

The most fundamental limitation of the EE study is the cross-sectional rather than longitudinal design. This means it is not possible to establish definitively the direction of any link between two variables using the results in this thesis alone. However, it is possible to judge the *more likely* direction(s) of effect by relating links between variables to other research studies and known theoretical relationships from the literature. Whenever a correlate of EE is identified in the present study, an attempt is made to discuss its possible direction(s) of effect.

11.2.2 Bias

Bias can be defined as any systematic errors introduced into a study that may lead to incorrect estimates of the associations under investigation. Scazufca (1996) identified three types of bias that are potentially relevant to this type of EE study.

(i) Selection Bias

Selection bias could have occurred for several reasons. First, the sampling was not epidemiological, which limits the generalisability of the results. Although a hospital admission was not necessary for inclusion into the study, patients did have to come into contact with hospital services in some way. This means that some first episode people, potentially with different socio-demographic, illness-related or carer profiles, may not have been included in the study. Also, not every first-episode patient identified was approached, because some were too ill and others were transferred to a hospital out of the area before they could be approached. The high proportion of patients and carers from ethnic minorities and the urban sampling of the study limits generalisability to more rural geographical areas. The refusal rate for entry into the study was low and those who refused were similar to those who consented. However all three carers who refused were black compared to 34.5% of the consenting group, suggesting that the results are less representative for black than white people, although ethnicity was not associated with EE. All three carers who refused already had a close relative diagnosed with psychosis, suggesting that the results are more relevant to carers who are new to being involved with a psychosis patient. However, since the study aimed to examine *new* carers, this bias may actually enhance the validity of the study.

(ii) Observer Bias

All the assessments were carried out by the same person, which might have biased the EE ratings in line with participant's scores on the explanatory variables. However, the EE tapes were usually rated several weeks or months after the patient and carer interviews and so it is unlikely that knowledge of the explanatory variable scores influenced the EE ratings. Also, the EE inter-rater reliability ratings were above acceptable levels.

(iii) Data Input Errors

In order to avoid data input errors the data file was scanned for rogue values and in each analysis outliers were checked. However, since data input errors are non-systematic, the effect of any data input errors would be to dilute the relationship between explanatory variables and EE. Therefore the significant links between EE and other variables are not invalidated by the possibility of data input errors.

(iv) EE Co-Morbidity

EE co-morbidity was common and in some ways this represents a potential difficulty for understanding the genesis of specific EE components (although in other ways it is potentially theoretically informative). Some attempt has been made to tease out the different contributions High CC and High EOI might make to the variance. However, H was too commonly co-morbid with High CC for this to be possible. Therefore it is not possible to quantify the extent to which any differences found between EOI and CC might be due to some combination of CC with H.

11.3 PART 2: TEST OF THE STUDY HYPOTHESES

11.3.1 Is Coping Associated with EE?

Birchwood and Cochrane (1990) reported that psychosis carers who were with patients who had a mean illness duration of 2.6 years had adopted *styles* for coping. The present study demonstrates that even as early as 19 weeks (carers were interviewed on average one week after the patient interviews) new carers have adopted detectable styles of coping. This replicates a recent study at the first episode which did not involve EE (Tennakoon et al. 2000).

Furthermore, coping style is able to differentiate High from Low EE carers, as Birchwood and Cochrane (1990) suggested.

The hypothesis that more avoidant coping would be reported by High EE carers was supported. This is consistent with the cross-sectional studies of Bledin (1990), Scazufca and Kuipers (1996), and the follow-up study of Scazufca and Kuipers (1999). In the present study it was found that avoidant coping was used significantly more frequently by all five High EE groups. This pattern of links is different to Scazufca and Kuipers (1999) who reported that avoidance was mainly linked only with higher EOI. It is possible that at the first episode the sample contains a higher proportion of people who are both critical or hostile and also using avoidant coping. Later in the illness such carers may have broken contact with patients, unlike High EOI carers who continue to engage in avoidance coping but do it within the context of over-protection. With reference to particular sub-scales of avoidant coping, behavioural disengagement was the most consistently associated whereas denial was not used significantly more by any of the High groups.

The avoidant coping association with EE is consistent with carers perceiving themselves to cope less effectively (Smith et al. 1993). This confirms the early observation that High EE carers use more coping that is less helpful (e.g. Kuipers et al., 1983). The avoidant coping link with EE is also consistent with High EE carers perceiving that their situational stress exceeds their own capacity to deal with it (Barrowclough & Parle, 1997). So the results in this study extend the importance of avoidant coping to the early phase of EE. This supports Barrowclough and Parle's (1997) view that maladaptive cognitive appraisals may maintain a High EE response, extending the evidence base for it to the start of caring.

11.3.2 Is Burden Associated with EE?

(i) Total Burden and EE

In line with the hypothesis, High EE carers had significantly higher burden scores, so the results of this study extend the importance of burden to the early development of EE. This is consistent with four cross-sectional studies (Jackson et al., 1990; Smith et al., 1993; Scazufca & Kuipers, 1996; Bogren, 1997) and three follow-up studies that addressed the issue (Scazufca

& Kuipers, 1998; Bentsen et al., 1999; Lenior et al., 2000). Results indicated that overall High EE and the three component High EE groups had significantly higher burden scores. This is in contrast to Bogren (1997) who found that only CC and H were associated with burden. The logistic regressions indicated that avoidant coping style not burden was generally the best predictor of EE status. This is different to the cross-sectional study by Scazufca and Kuipers (1996), since burden was included in the multivariate model that was constructed. However, burden and coping are thought to interact with each other (e.g. Szmukler et al., 1996), and in the present study a further analysis revealed that burden and avoidant coping were highly correlated ($r = .64$, $p < 0.01$). So the present study's burden results complement rather than precisely replicate the study of Scazufca and Kuipers (1996). Interestingly, burden was not significantly higher in carers who were High CC without High EOI. However, as noted in the results (Chapter 8), a general finding was that both CC and EOI appeared to contribute to the variance of appraisal variables.

(ii) Areas of Burden and EE

It was hypothesised that all areas of burden would be higher in all the High EE groups.

a) Difficult Behaviours

The only area of burden that was associated with the overall EE classification and the three High component groups was difficult behaviours. Several other studies have found that difficult behaviours were associated with High EE overall, High CC and Hostility (e.g. Barrowclough et al., 1997; Bentsen et al., 1998c), although High EOI has been a less consistent link in the literature (e.g. Bentsen et al., 1996a). However, carers who were High CC without also being High EOI did not have greater burden in this area.

b) Effect on the Family

The finding of higher burden in the area of 'effect on the family' for H carers is different to Bentsen et al., (1999) who found no association with H. Instead, they found that higher scores on this variable were associated with, at admission, an unstable pattern of CC, and at follow up, High-High EOI and EE patterns rather than Low-Low patterns.

c) Negative Symptoms

Although EE was not significantly associated with negative symptoms, there was a strong trend for High CC carers to report more burden in this area. This is consistent with studies of the attributions of High EE carers for negative symptoms (e.g. Harrison & Dadds, 1998).

d) Loss

Loss was significantly higher for carers who were overall High EE, H, High EOI, and High CC was almost significant. The results support the importance of the area of loss for High EE carers (Patterson et al., 2000). However, the results differ from the study by Patterson et al. in that High CC carers had almost significantly more loss, not less. This might have been due to the fact that 5/15 of the High CC carers were also High EOI, since High CC carers who were not also High EOI did not have even a trend for more loss than the Low EE group. However, they still did not have significantly less loss, as Patterson et al. found. It is difficult to compare the two studies on this aspect because the baseline EE co-morbidities between High CC and High EOI in the study by Patterson et al., were not reported. It is possible that there was a higher level of co-morbid EOI and CC in the present study, even when High EOI carers are taken out of the analysis. Also, the studies may not be directly comparable because the instruments used to measure loss are different.

More problems with services were reported by H, High EOI and High CC carers, and High EE carers overall reported similar problems at an almost significant level. Finally, more problems with the dependence of the patient were reported by High EOI carers.

(iii) Burden Summary

The present study thus extends an association between EE and its components with burden and its sub-areas, to the first episode of psychosis. The main finding of higher burden in High EE carers is consistent with the view that burden may be involved in the mediation of a High EE response i.e. High EE may be a way of coping with the burden (Scazufca & Kuipers, 1996), perhaps from the start of caring.

11.3.3 Is Perceived Patient Social Functioning Linked To EE?

The hypothesis that first episode High EE carers would perceive more social functioning deficits in patients was supported. Whilst High CC and Hostile carers perceived more social deficits, High EOI and EE overall group scores fell short of significance but were in the expected direction. High CC carers who were not also High EOI did not report more social functioning deficits. The results are therefore broadly consistent with studies later in the course of psychosis which found that High EE carers perceived more social deficits (e.g. Barrowclough & Tarrier, 1990; Smith et al., 1993; Scazufca & Kuipers, 1996). In finding that early overall EE was not significantly associated with the social functioning score, the study agrees with the first admission study by Huguelet et al. (1995). Huguelet et al. found a difference only after three years, although the social functioning of patients was assessed by investigators not carers. So this study extends a link between perceived social functioning and EE to the first episode. On the issue of which areas of social functioning were lower, interpersonal functioning was the main association across High groups. Using the SFS, Smith et al., (1993) also found this scale to be lower in the High EE group. In the present study, High EOI carers reported more problems in two areas where other high groups did not. These were independence: competence and social withdrawal. This appears different to Barrowclough and Tarrier (1990) who found that H was the main link with High groups. Thus an association between EE and social functioning may be stable across illness phases, but the areas of social functioning which are associated might differ by component through the course.

11.3.4 Are Distress and Depression Associated with EE?

The hypotheses that first episode High EE carers would be more distressed and more depressed were not supported. The absence of any significant associations between GHQ-distress and EE is in line with Barrowclough et al. (1996) who also did not find a link in a cross-sectional study. Perhaps a follow-up to the present study would reveal a relationship across time, similar to the studies of Barrowclough and Parle (1997) and Boye et al. (1998). The suggestion that depression may be associated with EE (Scazufca, 1996, p. 232) was not supported, as both groups displayed similar levels of depression. The absence of a cross-sectional link between EE and distress and depression therefore appears to be the case across different phases of the course of psychosis. Distress and depression may have been unrelated to EE status because they are non-specific indicators of a stress response i.e. unlike burden,

coping and social functioning, they did not specifically tap thoughts and behaviour surrounding the caring situation.

11.3.5 Are Patient Illness-Related Characteristics Associated with EE?

The illness-related characteristics tested with EE were symptom type and severity, age of onset, illness length and diagnosis. The results indicated that there were no credible associations between EE and illness-related factors.

The absence of a link between EE and diagnosis agrees with previous early phase EE studies (e.g. Linszen et al., 1997). The finding that symptom profile was not associated with EE agrees with some studies (e.g. Miklowitz et al., 1983; Vaughn et al., 1984; Scazufca & Kuipers, 1996) but not others (e.g. Glynn et al., 1990; Bentsen et al., 1998c). It might have been expected that High EE carers would be paired with patients who have more negative symptoms (e.g. Moore et al., 1992) or more positive ones (e.g. Glynn et al., 1990) but this was not the case. On the other hand, it will be recalled there was a strong trend for negative symptoms to be higher in the High CC group but this was when the carer was judging the symptom. The lack of an association between symptom severity and EE agrees with some studies (e.g. Brown et al., 1972) but not others (e.g. Glynn et al., 1990; Bentsen et al., 1998c). However, the time-lapse between the SCAN symptom period rated and the carer assessment might have diluted any relationship that exists between EE and symptom type, severity and diagnosis. A more concurrent approach to assessment may be required. Also, more sensitive ways of assessing symptoms might reveal a connection, for example, using the BPRS (e.g. Glynn et al., 1990) or assessing for sub-clinical psychopathology (e.g. Simoneau et al., 1998).

With reference to the illness length, the result is consistent with findings from several studies (e.g. McCreadie & Robinson, 1987; Stirling et al.; Tanaka et al., 1995; Hooley & Richter, 1995). On the other hand, the illness length was approximately equivalent to DUP, and some studies have found an association between a longer DUP and more CC (e.g. Patterson et al., 2000; MacMillan et al., 1986). In the present study the absence of a relationship was confirmed in a post hoc correlational analysis of the two tested as continuous variables. However, the study did not attempt to quantify carer's exposure to symptoms, which might be a more sensitive measure. The short illness length of the patient sample (median 19 weeks) suggests

that the transactional development of EE might occur relatively quickly in some cases. Alternatively, it may be that EE does develop more slowly but begins in the prodromal phase. Gleeson et al. (1999) discusses transactions between the fairly non-specific changes in the future psychosis patient's behaviour and the carers view of the patients altered behaviour. However, so far, only the EOI component of High EE has been found to be present before onset (Miklowitz et al., 1983).

One way of interpreting the general lack of association between EE and illness factors is to argue that this is because EE is more related to carer's appraisal of patients functioning than objective symptoms (Scazufca & Kuipers, 1996). However, some of the present study's illness measurements may have been insufficiently concurrent and sensitive. So whilst this study does not support a first episode EE-symptom link, more valid assessments on the issue are needed.

11.3.6 The Strongest Independent Predictor of EE

The multivariate analysis showed that avoidant coping was the strongest independent predictor of EE across all measures. However, it varied in its ability to detect High groups, improving chance by a relatively modest 20% for High EE overall, 16% for High CC and 14% for H. Its real predictive power lay in its ability to detect Low EE where it existed, correctly classifying 82%-96% of Low EE carers, depending on which High measure it was contrasted with. The threshold appeared to be that Low EE carers, on average, used each avoidant strategy only rarely, whereas High carers did so more often. A less-than-linear relationship between avoidant coping and EE components may have been responsible for the poor performance of avoidant coping at detecting High EOI and High CC not High EOI (both 10% worse than chance). This suggested that the appraisal variables were fairly crude constructs for understanding EE, i.e. they were only tapping the nature of EE in a fairly blunt or distal way. Also, since avoidant coping was significantly associated with all High measures, it was not able to differentiate between components.

11.4 PART 3: THEORETICAL IMPLICATIONS OF THE EE RESULTS FOR MODELS OF EE AND PSYCHOSIS

The aim of the present study was to test if a carer appraisal model was valid at the first episode, as in Patterson et al. (2000), using variables that had never been tested before at this phase of the illness which seem useful later in the course of psychosis (Scazufca & Kuipers, 1996; Smith et al., 1993; Barrowclough & Parle, 1997). The results suggested that a carer appraisal model is helpful in understanding the genesis of High EE and its components at the first episode of psychosis. Carers who are High EE appear to perceive their caring situation, although perhaps not their general life situation, in a way which is more stressful than Low EE carers. Lazarus and Folkman's stress-coping framework (as outlined in Chapter 4) can help to explain High EE. Thus within *primary* appraisal, carers who develop high EE may appraise the illness of the patient as relevant to their own goals in life ('relevance'), as incongruent with their goals ('congruence'), and as interfering with particular goals which will vary across carers ('type of ego involvement'). Secondary appraisal may then involve a pessimistic judgement about the situation improving ('future expectancy'). Thus, in contrast to Low EE carers, they generally try to avoid the stress they are facing, experience more burden and perceive more social problems in the patient. A secondary aim of the present study was to test if carer appraisal factors were stronger independent predictors than illness related factors. This study found that the objective illness was not predictive of carers EE status. However, other more valid measurements might find consistent associations with illness.

In some ways the fact that EE appears to be primarily associated with carers cognitive appraisal should not be surprising. In the field of emotion (e.g. Strongman, 1996) and the field of emotional disorders (e.g. Clark, 1999), cognitive appraisal is recognised as the most proximal (Perrez & Reicherts, 1992) and important (though not the only) influence in the generation of emotion. The thesis results suggest that appraisal variables which are associated with EE may be the same at different phases during the course of psychosis. Within each type of variable, however, there may be changes in the EE components which are linked, such as the areas of social functioning or burden. Given that the median illness in the present study was only 19 weeks, the appraisal which leads to High EE may develop quite quickly. The results also suggest that carer's appraisal may be the key to lowering High EE or preventing it from developing at the first episode. As such, there are implications for stress-vulnerability

frameworks of psychosis (e.g. Nuechterlein et al., 1992). The results help to specify a circumstance which might predict a lower likelihood of positive symptom re-emergence during the early phase of the disorder. When carers rarely use avoidant coping strategies with the patients illness, there is a very good chance that they are Low EE. If carers report using such strategies more often than this, then there is a moderately increased risk that they are High EE.

The exact nature of carer's appraisal is presently uncertain. The fact that distress and depression were not associated with EE might mean that carers have a core stress appraisal which is more specific than just generally perceiving more stress in their lives in general. Distress and depression may have been non-significant because, unlike burden, coping and social functioning, they did not tap the specific caring situation; they are non-specific indicators of a stress response. This implies that research efforts should more profitably focus on cognitions about caring rather than general trait features of the carer.

Different components of EE are often present in the same carer at the same time, suggesting a common core appraisal might drive High EE (e.g. Greenley, 1986). At a higher level of abstraction the content might be conceptualised as a catastrophic appraisal of the role of caring for the patient. Carers with this sort of appraisal might attempt to help the patient, but when this fails to improve the illness or lower their negative feelings associated with caring, their attempts may become ever more extreme until a point of High EE is reached. The precise nature of such a possible catastrophic appraisal is not known. Barrowclough and Parle (1997) conceptualise it in terms of 'threat' (in Lazarus & Folkman's framework a 'future harm') whereas Patterson et al. (2000) use the appraisal concept of 'loss', but specify that CC and EOI differ in their relationship to the loss. Different components of EE do have a range of shared and different correlates, suggesting that there are differences in appraisal underlying CC/H and EOI. In order to understand the precise nature of EE and its components, it will be necessary to test variables which have much more specificity than the variables used in the present study.

11.5 FUTURE RESEARCH DIRECTION FOR EE

Understanding what, in fact, influences High EE to develop should be the most important aim of EE research. Carers appraisal seems the most promising locus upon which to focus efforts.

What is needed next is a thorough analysis of carers' appraisal using quite specific cognitive variables which might be able to differentiate between High EE components. Testing all the main cognitive factors so far identified in the literature, in one sample at the same time, seems an appropriate first step in penetrating into the deeper nature of the appraisal. Work should also continue with attempting to identify subtle patient factors and broad situational influences, as they will be important for a full model of EE. However, cognitive appraisal seems the most fruitful area to research. It seems important to routinely attempt to test out the hitherto neglected possible interactional influences of co-morbid High EE components. A multivariate approach seems vital in order to identify the strongest independent correlates. Assessing EE across time in relation to correlates will be helpful for making more definitive causal statements. Such a design may also shed further light on a transactional model of EE development. However, studying individual EE components itself might not be sufficient. The EOI categorisation is broad and it seems possible that there are distinct sub-groups, such as carers who score a '3' due to distress, whilst others who score a '3' due to over-protection. This sort of approach might also help to specify appraisal facets. Identifying more precisely the nature of High EE carers appraisal may well provide highly specific cognitive targets which CBT could tackle in order to lower or prevent EE from developing. If this can be achieved at the first episode, then it is likely to benefit both carers and patients.

11.6 PART 4: CLINICAL IMPLICATIONS OF THE EE RESULTS

11.6.1 Early Engagement of New carers

The low refusal rate of the present study (only 3/49 carers refused) suggests that carers can be successfully engaged at the first episode. Interestingly, all three carers who refused already had relatives who had been treated for psychosis by the service, implying that the first episode might be the most successful time to engage them.

11.6.2 Is High EE Prevalent Enough to Target at the first episode?

The finding that High EE carers were present at the first episode in a clinically significant proportion (43.5%) supports other studies that have also found sizeable proportions of High EE carers in the early psychosis phase (as discussed in Chapter 4). The present study therefore supports the relevance of intervening in order to lower EE even at the first episode.

Furthermore, the study indicates that all three components of High EE may be relevant intervention targets as early as 19 weeks after the onset of positive symptoms.

11.6.3 What Should Be Done to lower or prevent EE after the first episode?

Since EE at the first episode appears to show the same associations as later in the course of psychosis, and since intervention studies have been highly successful, this suggests that those same interventions may work with similar levels of success at the first episode too. In suggesting what might improve the effectiveness and efficiency of interventions, the results here suggest that lowering carers' stress appraisal specifically of the illness situation may be important (Barrowclough & Parle, 1997; Patterson et al., 2000).

There has been recent interest in offering individual cognitive behaviour therapy to new patients with psychosis (e.g. Haddock et al., 1999). The results from this study, suggest that individual cognitive behavioural therapy, as is commonly used successfully for a wide range of emotional disorders, could also be effective at lowering EE level. Given the importance of a High EE classification to patient and carer outcome, even for early patients and carers (as discussed in Chapter 4), offering individual cognitive behaviour therapy to new High EE carers would seem prudent.

Aside from individual cognitive behavioural therapy with carers, interventions which alter the carer's environment might also reduce their stress appraisal of their caring role and so lower EE. Intervention focused on patients' objective social functioning, and whatever the carer defines as 'difficult behaviour', would seem likely to lower perceived stress of caring. Increased social support, such as a carers group (Fadden, 1998) for High EE carers might also lower the perceived stressfulness of caring.

11.6.4 Earlier and Quicker Identification of High EE?

The identification of High EE using the CFI is a time and labour intensive practice. This is a major barrier to the EE measure being used in routine clinical practice. Attempts so far to construct quicker assessment instruments have not been sufficiently valid at detecting High EE (e.g. Magana et al., 1992), but the effort to find a short-cut method is continuing (e.g. Fearon et al., 1998; Shimodera et al., 1999; Moore & Kuipers, 1999). Increased understanding of EE's

correlates should assist in the construction of such instruments. The results from the present study suggest that a short questionnaire which simply aims to assess cognitive appraisal features such as the perceived stress of caring and mastery of the illness situation, rather than labour intensive ratings of emotionality, may prove to be a short-cut to predicting High EE and psychosis relapse. This is open to empirical testing.

In the absence of a validated alternative to the CFI, the multivariate results of the present study are mainly able to help detect Low EE carers. If a carer is Low EE, there is a very good (82-96%) chance they will be using avoidant coping strategies, on average, rarely or less. This might help with carer therapeutic prioritisation. The search for a short-cut method to establish EE status should be another future research priority, as it will enable the possibility of early individual cognitive behavioural therapy or family interventions to lower carers' EE.

11.6.5 Outcome Indicators of Intervention?

The results presented in this thesis suggest that carers' avoidant coping could be a potentially useful outcome indicator to evaluate the results of an intervention.

11.7 SUMMARY OF CHAPTER 11

This chapter discussed the findings of the EE study. The main aim was to test the validity of a carer appraisal model of EE, and a secondary aim was to examine if carers appraisal was a stronger independent predictor of EE than patient illness-related factors. It was the first study to test several variables that have been found to be associated with EE later in the course, in a group of exclusively first episode patients and their carers. Individual components of EE were also tested with the explanatory variables. The main limitation of the study was its cross-sectional design.

The results supported the validity for using a carer appraisal model to understand EE at the start of the illness. High EE and its components were associated with carers avoidant coping, burden and perception of social functioning. EE components showed a mix of shared and different correlates on burden, coping and perceived social functioning. Distress and depression were not associated with EE, perhaps because they are non-specific indicators of a stress response, and not tied specifically to the caring situation. Illness related factors were not

associated with EE. Avoidant coping was the strongest independent predictor of EE. However, it was unable to differentiate between the EE components. Avoidant coping used less rarely or less often was a strong predictor of Low EE. However, avoidant coping used more than rarely was only a modest predictor of High groups. This was because variables were less-than-linearly linked to EE, and these two latter results suggested the variables in the study were fairly blunt at explaining High EE.

The exact nature of carer appraisal is presently uncertain and more specific cognitive variables may be useful in delineating appraisal facets. Testing all the main known cognitive factors, particularly those which are related to the caring situation rather than trait measures, in the same sample using multivariate statistics would be a useful first step. Refining the EOI category might also help with making specific links. Identifying the precise nature of carers appraisal may reveal highly specific targets for CBT, in individual or group formats, to lower or prevent EE from developing at the first episode.

Conclusions to Psychosocial Stress and the First Episode of Psychosis

Stressful Event-First Onset Study Conclusion

This thesis has added to the evidence that stressful events may play a role in the initial onset of psychosis. Further, it has found that events may exert an effect further back in time than the previously established three weeks before onset, and that the combination of event severity and independence might be important to the onset of some first episodes. The literature on psychosocial stress and depression shows there are a great many questions about events and first episode psychosis which remain unanswered, but which could be addressed using current technology. It is, perhaps, now time to move away from asking simple questions about whether a single type of stressor influences the expression of psychotic symptoms. Instead, it seems more theoretically useful to research how established multiple psychosocial stressors - such as events, types of events, EE, difficulties and types of difficulties - interact with each other and with vulnerability and protective factors. It has been shown in this thesis that events are common before the first episode and that they span a variety of types. Given that events have multiple attributes and psychosis has many facets, it is likely there are many hitherto undiscovered links between the two. Asking more specific questions about event attributes seems important. For example, this thesis has identified evidence that the independence of events might play a role in the external attribution error that is fundamental in psychosis. Using continuous measures between events and facets of psychosis is likely to be more sensitive at detecting links. Isolating and quantifying the effects of psychosocial stress at the first episode is likely to provide guidance to early intervention to improve patient affect, psychotic symptoms and may also inform the new drive towards the prevention of some new cases of first episode psychosis.

Stressful Event Delusional Theme Study Conclusion

The present study has found that nearly half of people who present with first episode persecutory delusions have actually experienced at least one fairly severe uncontrollable intrusive event in the year before onset. This contrasts with the, albeit small, group of people who did not have the symptom and did not experience such an event. The extremely unpleasant

nature of many of the intrusive events was such that a person not vulnerable to psychosis might well, afterwards, experience a degree of schema change concerning external harm. For people vulnerable to psychosis, the event may have influenced the 'biased theory of mind default setting about the intentions of others', and encouraged the 'excessively external and specific attributional style' which is characteristic of persecutory delusions. The intrusive event-persecutory delusion hypothesis results require replication with a larger non-persecutory comparison group. Although tentative, the association found in the present thesis begs the question of what other links there may be between events and delusional themes. Testing it specifically with 'poor me' (in comparison with) 'bad me' paranoia seems worthwhile. Given the co-morbidity of themes and the co-traumatic nature of events, future hypotheses are likely to need to possess both 'event-specificity', 'theme-specificity' and be able to demonstrate both in multivariate statistical tests. Attempting to establish specific psychosocial stress-delusional theme links is a relatively untapped and uncharted area, yet it may well hold the potential for improving cognitive-behavioural interventions for delusions.

Expressed Emotion Study Conclusion

This thesis has shown that a carer appraisal model is useful for understanding the genesis of High EE and its components. Indeed, it might be the most important influence on its development. High EE carers appear to appraise their caring situation as more stressful than Low EE carers, though, importantly, not necessarily their life in general. A key future research priority should be to identify more precisely the nature of this appraisal. Many cognitive correlates have already been identified and it may be useful to analyse and synthesise them, in a follow-up design. This is likely to provide a deeper penetration into the core appraisal processes which seem to underlie High EE and its components. Below the level of a core common appraisal in all High EE carers, there are likely to be differences in facets of appraisal between the High EE components. The hunt for the precise nature of the cognitive appraisal processes which may underlie High EE and its components is, perhaps, best guided by established cognition and emotion frameworks, such as those developed by Lazarus and Folkman (e.g. 1984) or Clark (e.g. 1999). Closing in on the deeper nature of the cognitive appraisal processes underlying High EE is likely to provide guidance on how to more effectively and efficiently identify, lower, or prevent it from developing. This may benefit both carers and patients.

General Conclusion to Psychosocial Stress and the First Episode of Psychosis

Using the unique advantages of a first episode design, this thesis has shown that the initial onset of psychosis is a time of serious psychosocial stress for most patients and their carers. Understanding the likely complex interactions between stressors and their possible multiple links to different facets of psychosis is likely to provide guidance concerning therapeutic targets. Cognitive-behavioural technology is well-established at effectively treating the effects of psychosocial stress, although it will need to be adapted to the unique needs of new patients and their carers. Within an 'early intervention paradigm' and a 'critical period hypothesis', evidence in this thesis has been presented about the prevalence and severity of psychosocial stressors around the time of the first episode. This evidence suggests there is major potential for reducing the deleterious effects of psychosocial stress on patients, carers, and their relationships.

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Appendix 1

STUDY OF THE EXPERIENCES OF PATIENTS BEFORE AND AFTER HOSPITAL ADMISSION: PATIENTS INFORMATION DOCUMENT

We are carrying out a research study at the Maudsley/Bethlem hospital on new patients. To do this we need to know how they are feeling at the moment and how they were before they came into hospital. By asking new patients what they have experienced we hope to understand the difficulties faced by them in order to help change hospital services, so that they are able to help people better. The study is being carried out by Professor Paul Bebbington, Dr. Elizabeth Kuipers and medical research worker David Raune.

David Raune would like to come and speak with you twice. The first time, he would like to find out about how you are at the moment and especially ask you about any difficulties or problems that you may be having. The second time, he would like to find out about how things were in the time before you came into hospital.

Anything you say would be treated in the strictest confidence. Permission will be asked to audio-tape some of what you say so that more of it can be remembered afterwards by David Raune. The information we obtain from you will eventually be recorded on a computer but your name will not be used. If you would like, after the study is finished, we can send you information about what we learn from speaking to new patients and how we think hospital services might be improved to help them better.

If you decide not to be part of the study this will not affect in any way the care you receive at the hospital. If you do decide to take part you are free to withdraw from the study at any time without having to say why. It would be very helpful if you would agree to be a part of this study so that your experiences can go toward making the patients services better.

If would like to ask any questions or want find out anything else at all please telephone David Raune on 0171-703 5411 Extension 3491, who will be happy to speak to you. He is based in:-

*The Social Psychiatry Section
12 Windsor Walk
Denmark Hill
London
SE5 8AF*

Appendix 2

STUDY OF THE EXPERIENCES OF PATIENTS BEFORE AND AFTER HOSPITAL ADMISSION: PATIENTS CONSENT FORM

I am signing here to say that I would be willing to take part in this study looking at patients experiences before and after hospital admission.

Signed:

Name in Block letters:

Dated:

Witnessed By:

Name in Block letters:

Dated:

Thank you very much for your participation in this study. Your help is greatly appreciated.

Appendix 3

STUDY OF THE EXPERIENCES OF PATIENT'S RELATIVES BEFORE AND AFTER HOSPITAL ADMISSION: PATIENT'S INFORMATION DOCUMENT

Thank you for agreeing to be part of our study on new patient's experiences before and after hospital. We are also very interested in the experiences of new patient's *relatives*. By asking relatives about their experiences we also hope to make services better for them as well as the patients. This research is being carried out by Dr. Paul Bebbington, Dr. Elizabeth Kuipers and medical research worker David Raune. David Raune would like to speak to your closest relative for about two hours in order to find out how things have been with them. Nine months after this he would like to speak with them again to find out how things have been since then.

The information we obtain from your relative will eventually be recorded on a computer but his/her name will not be used. Permission will be asked to audio-tape some of what he/she says so that more of it can be remembered afterwards by David Raune. If you would like, after the study is finished, we can send you information about what we have learned from the study and how we think health services might be improved in the future for new patients and their relatives. **Permission for us to ask your relative to participate in this study is entirely up to you**, you can withdraw it at any time without having to say why and this will not affect the treatment you receive. It would be very helpful if you would give permission so that their experiences can also go toward making hospital services better.

If would like to ask any questions or want find out anything else at all please telephone David Raune on 0171-703 5411 Extension 3491, who will be happy to speak to you. He is based in:-

*The Social Psychiatry Section
12 Windsor Walk
Denmark Hill
London
SE5 8AF*

Appendix 4

STUDY OF THE EXPERIENCES OF PATIENT'S RELATIVES: PATIENTS CONSENT FORM TO SPEAK TO RELATIVE

I am signing here to say that I agree to my relative being asked to take part in this study looking at patient's relatives experiences before and after hospital.

Signed:

Name in Block letters:

Dated:

Witnessed By:

Name in Block letters:

Dated:

Thank you very much for your participation in this study. Your help is greatly appreciated.

Appendix 5

PATIENT SOCIO-DEMOGRAPHIC FORM

* = database

MONEY: ----- (/ /)

Name:

Onset Date According to Notes:

Title:

* Number: (provisional / confirmed):

* Sex [**PSDS**]:

1= male 2= female

* Age: [**PSDA**]

* Ethnic Origin [**PSDEO**]: 1= European -White / 2= Black - Caribbean / 3= Black - African / 4= Indian / 5= Chinese / 6=Other

* Employment Status [**PSDES**]: 1= unemployed / 2= retired / 3= student / 4= part - time / 5= full-time

* Occupation [**PSDO**]:

* Marital Status [**PSDMS**]: 1= single / 2= married / 3= separated / 4= divorced / 5= widowed / 6= partner / 7= other

* Living with a partner [**PSDLWP**]: 1= Yes / 2= No

* Number of children living with before onset [**PSDNCLW**]:

* Household composition before onset [**PSDHCBO**]: 1= patient carer other adults / 2= patient carer / 3= patient other adults / 4= patient

* Psychiatric medication *after* admission [**PSDPMAA**]: 1= Yes / 2= No

* Compliance with psychiatric medication *after* admission [**PSDCMAA**]: 1= All the time / 2= Most of the time / 3= Some of the time / 4= Not at all

* Previous Psychiatric Admission [**PSDPPA**]: 1 = Yes / 2 = No

PATIENT SOCIO-DEMOGRAPHIC FORM / Cont'd.....

Date of Birth: / /

Address:

Telephone No.:

Hospital:

Hospital No.:

Date of Admission:

Ward / Community Team (a):

Ward / Community Team (b):

Consultant:

Senior Registrar:

SHO / Registrar:

Hospital / Community Keyworker:

Possible Relative :

Relative Tel no.:

Relative Address:

Scan Sections Priority:

* Scheduled *Scan* Interview Date:

* Scheduled *Leds* Interview Date:

* Psychiatric Medication *just before* Admission [PSDPMBA] : 1= Yes / 2= No

* Compliance with medication *just before* admission [PSDCMBA]: 1= All the time / 2= Most of the time / 3= Some of the time / 4= Not at all

Organic Evidence:

Substance Abuse:

PATIENT SOCIO-DEMOGRAPHIC FORM / Cont'd.....

Relevant Background History:

Situation Now: (family, work, etc)

General Psychopathology

Psychosis evidence:

Theme Evidence:

Grand:

Persy:

Depress:

Reference:

Additional Miscellaneous Patient Sociodemographic Information

Appendix 6

DEMOGRAPHIC QUESTIONS

(This schedule has been designed to use as a form that is filled in by the interviewer while asking the questions.)

ID _____

1. How old are you?

AGE _____

MARITAL STATUS

2a) Are you married. Living with someone?
Since when?

(Record if single
married
cohabiting _____)

If single: Do you have a boy/girlfriend?
How long have you known them for?

b) Have you ever been divorced/separated or widowed?

c) Or lived with anyone (else) in the past?
How long for?

Record if widowed
divorced/sep from spouse
ever separated from a cohabitee _____

3. a) Do you have children?

If yes - how many?
Record number of children _____

b) Have you ever lost a child?

How? _____ When? _____ What ages (were they)? _____

Record ages and reason for loss _____

4. Do you work?

What is your job?

Record type of job _____

How many hours a week do you work?

(distinguish especially 30+hrs (full-time))

Record number of hours _____

How long have you had that job?

Record length of present job _____

5. Does your spouse/partner work?

What is his/her job?

(If self-employed find out number of employees.)

(Find out whether manager/supervisor.)

Record type of job _____

HOUSEHOLD MEMBERS

6. How many people are living in the present household?
Who is that? (List household members)

| <u>Relationship</u> | <u>Age</u> | <u>Name</u> | <u>Occupation/type school</u> |
|---------------------|------------|-------------|-------------------------------|
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |

SOCIAL CONTACTS

7. Do you see any other relatives?
How often?
What about in-laws? (list)

| <u>Relationship</u> | <u>Approx. frequency of contact</u> | | <u>Location</u> |
|---------------------|-------------------------------------|-------------------|-----------------|
| | <u>Visual</u> | <u>Non-visual</u> | |
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |

8. Can you tell me about the friends and acquaintances you see regularly? What about neighbours? Work associates?

| <u>Relationship</u> | <u>Approx. frequency of contact</u> | | <u>Location</u> |
|---------------------|-------------------------------------|-------------------|-----------------|
| | <u>Visual</u> | <u>Non-visual</u> | |

INTIMACY CONTEXT

9a. If you had a problem of some sort who would be the first person you would want to discuss it with? (If not mentioned -

i) what about your husband/wife?

ii) Anyone else?) What about and?

(Check friends in 8 above. Then if there are no confidants, identify of "main friend" can be established i.e no confiding but frequent contact.)

Name & frequency of contact

9b. If you had been asked this question a year ago would there have been anyone else you might have mentioned then?

Anybody you wouldn't have mentioned then?

(Again, probe about main friend if no confidant.)

CHILDHOOD

10. a) Where were you born? If relevant: When did you come here?

b) Do you have brothers and sisters? No. _____
What position are you in the family?
(Only, eldest, middle, youngest)

Have any of your brothers or sisters died? When was that?

c) Are both your parents alive?
If so - What age are they?

Mother's age _____ Father's age _____

If not - What age were you when they died?

S's age at mother's death _____

S's age at father's death _____

d) Have your parents ever been separated?

If yes - when was that?

S's age when parents separated _____

e) Were you ever separated from your mother before age 17?

If yes:

How old were you? _____

How long was it for? _____

(Was it for more than a year?)

What was the reason for the separation? (e.g. work, ill health, marital separation)

f) Were you ever separated from your father before age 17?

How old were you? _____

How long for? _____

What was the reason for separation? (e.g. work, ill health, wartime, marital separation)

g) So who brought you up for most of your childhood?
(Ask about surrogate parents)

Appendix 7

LIFE EVENTS AND DIFFICULTIES INTERVIEW SCHEDULE

ROYAL HOLLOWAY
UNIVERSITY of LONDON
11, BEDFORD SQUARE
LONDON WC1B 3RA

February 1993

INTERVIEW SCHEDULE FOR EVENTS AND DIFFICULTIES

(For use with the LEDS-2; 19/6/89)

MRC team,
RHBNC, Univ of London,
11, Bedford Square,
London WC1B 3RA,
UK.

THE UNDERLINED QUESTIONS ARE THE STANDARD ONES WHICH HAVE TO BE ASKED IF THE POINT HAS NOT ALREADY BEEN COVERED. THE OTHERS ARE SOME SUGGESTED ADDITIONAL PROBES. MATERIAL IN 'BOXES' AT BEGINNING OF SECTIONS ARE SOME SUGGESTED PROBES ONLY FOR USE ONCE AN EVENT/DIFFICULTY HAS BEEN ESTABLISHED.

Note:

- i) At the first stage of the depression research, for methodological reasons questions about events were asked separately from those about difficulties; they are now asked about simultaneously. The older procedure can be adopted if required.
 - ii) The 'questions' are often in the form of a reminder to the interviewer of what to cover in questioning.
 - iii) This version of the schedule is designed to cover the period from B (the 12-month point before onset, the date of which must have previously been established) up till interview (I). It can, of course, be amended - e.g. in work concerned only with onset and not course so that only the 12-month period from B to C1 (onset of disorder) is covered.
* * * * *
- A. Once an event has been established, question in detail about incidents leading to it, or stemming from it (e.g. decisions preceding a job change or a marriage) in order to establish contextual threat. Use 'boxes' at beginning of sections.
- B. Make sure to relate each event to:
i) change-points (e.g. onset case depression),
ii) other events or difficulties.
- C. Make sure the respondent knows the range of people routinely included (see over).
- D. The interview schedule has been phrased for female subjects. The wording will have to be changed in accordance with the sample.
- E. Remind the interviewee from time to time during the interview both about these terms and about the period of time to be covered by your particular study.

Now I'd like to ask about the period since.....(IDENTIFY PERIOD AROUND ONSET IF RELEVANT)
and a bit before - that is the period since ... (e.g. 'AUGUST 1985').

I'm going to be asking you questions about things that may have happened to you or to people close to you, and by close I mean your:

Husband/boyfriend,
Children (including foster/adoptive children),
Brothers/sisters,
Parents,
Other household members,
Confidants (or main friend if none).

SECTION I - HEALTH

A.

FOR ANY KEY ILLNESS EVENT/DIFFICULTY, SOME SUGGESTED 'PROBES':

FROM DOCTORS:

Reasons for illness.
Chances recovery/outlook.
Treatability.
Future health; implications for work.
Has anyone else had it in the family?
Lack of information from doctor.
Shortcomings in care.

IMPACT ON:

Employment; chance of losing job.
Sick pay; problems obtaining suitable care.
Manifestations.
Handicap. How needed to cut down?
Pain, symptoms.
How long in bed?
Interference with everyday life/hobbies/ future plans.
Had before? Outcome.

ILLNESS OF OTHERS ONLY:

Was it expected?
How involved were you?
Nursing; infectiousness.
Worry about dying.
Worry handicap.
Diet; incontinence; lifting.
Change behaviour/personality e.g. anger, irritability,
ingratitude, blame?
Stigma/embarrassment?

Has anyone in the family been ill?

What about you?

Your husband or children or parents? (etc)

How serious was it? Was it an emergency?

REFER TO BOX 'A', PAGE 2

Has anyone been admitted to, or left, hospital in the time since... (e.g. 'August 85')

For what?

Was it an emergency?

General/local anaesthetic? How long for?

Problems during hospital stay?

REFER TO BOX 'A', PAGE 2

Have any relatives or close friends died?

What of? (USE BOX 'A', PAGE 2 IF NECESSARY)

Did you expect it?

How often seen before/during illness?

Were you involved at all?

Were you present?

Did you have to comfort the bereaved?

Any problems over arrangements for the funeral, or the will?

Impact on S's way of life.

Has anyone else you know died?

Who? (How long known, how often seen?)

Any surgical operations in the time since ... (e.g. AUGUST 1985) ... to self, child or parent, siblings, friends?

Have you had any bad news about illness that's been going on for some time?

Are there any chronic health problems?
For yourself or close relatives/friends?

e.g. Does anyone suffer from any of the following?:

Any chest troubles.
High blood pressure.
Heart trouble or stroke.
Varicose veins or piles.
Asthma.
Tuberculosis.
Chronic bronchitis.
Gall bladder or liver trouble.
Stomach ulcer.
Any other chronic stomach trouble.
Kidney trouble, or trouble passing water.
Arthritis or rheumatism.
Nervous trouble or psychological disturbance of any kind.
Diabetes.
Thyroid trouble.
Blackouts, fainting attacks or dizzy spells.
Repeated trouble with back or spine.
Chronic skin trouble.
Hernia or rupture.
Epilepsy (or fits).
Migraine.
Trouble with periods, or other gynaecological trouble, or trouble over contraception?

Have you any relatives who are a worry to you for other reasons?

Your close friends?

Because of old age? e.g. dementia; or disability.

Or a drinking or gambling problem?

Mental handicap, or anything else?

How about drugs?

Treatment/official contact re abuse?

In the time since ... (e.g. 'AUGUST 1985') has there been any nervous trouble in the family?

Among your close friends?

Has anyone been referred to a psychiatrist/psychologist?

Or been treated at a psychiatric out-patient clinic, hospital, or child guidance clinic?

What about your husband/parents/siblings?

Has there been any attempted suicide?

Has this ever happened in your family outside this time?

IF DISABILITY IN CHILDREN, ASK:

Do you have trouble obtaining: recognition?
 help?
 a diagnosis?

What were you told about: outcome?
 its implications?
 it running in the family?

PROBES CHILD'S DISABILITY:

Effect on behaviour (incontinence/ disturbance).

Effect on personality/ performance (IQ).

Special school? Extra therapy/classes?

IF YES? How long will he/she attend?

Are you worried about managing when he/she grows up?

Have you any plans about this?

IMPACT ON S:

Supervision, care, nursing.

Changing routine/employment.

Chance of a break. Respite care.

Interference with social life.

Special help apart from schooling/therapy.

Help from social services/self-help organisations.

Equipment, modification to home.

Member of supportive association.

REACTION OF HUSBAND/ S'S OTHER CHILDREN/OTHERS?

Relationship with child.

Stigma.

Have there been any accidents?

On the road, or in the home? etc.

What about the children?

Have you been involved in or witnessed any road accidents?

Or anything like that?

How did it happen?

How serious was it? Damage?

Who was hurt?

How far were you involved?

Insurance. Courts.

Has there been any pregnancy in the family, among close friends?

IF YES: Was it planned?
Impact on finance/career plans.
Housing implications.
Complications in previous pregnancy/birth.
Hospital admission.
Spouse/partner's reactions.
Other's reactions.

IF UNMARRIED:
Did you consider termination ... or marriage?
(TAKE ACCOUNT HERE OF RELIGIOUS BELIEFS).

Any miscarriages or abortions?

ASK IF: (i) MARRIED AND 16-45, OR
(ii) NON-MARRIED WOMEN UNDER 35 WITH A REGULAR BOYFRIEND
IN ... (e.g. AUGUST 1985).
OTHERWISE USE JUDGEMENT:

What about you - have you been pregnant or would you like to have been?

Or worried that you might be?
Did anything go wrong during the pregnancy?

Were any babies born to family or friends?

Complications at birth or afterwards.
Health of baby/mother.
First arrival home e.g. sleeping, feeding.
Other children.
Help in home.

Has anyone lost a baby?

Have any grandchildren arrived?

Has anyone close been trying to become pregnant and had problems with that? _

SECTION II - ROLE CHANGES

B.

FOR ANY INTERACTION CHANGE EVENT:

Temporary. How long away.
How often seen before the change?
How much did you do together?
How often do you see now?
Distance.
Telephone contact.
How did you get on? How about now?
Preparation. Evidence rejection/guilt.

INCREASE IN INTERACTION:
How fitted in - space/tension.

C.

FOR ANY MARRIAGE/ENGAGEMENT INVOLVING S:

How long known.
Complications/'delaying tactics'/rejections.
Family reactions.
Was there anything about him made you uneasy?

Has anyone in the family got married in the time since ...
(e.g. 'AUGUST 1985')?

What about your brothers, sisters, parents, children, friends?

*** REFER TO BOX 'B' ABOVE ***

Anyone engaged?

What about your brothers, sisters, parents, children?

When was this? When was it decided?
When was it first made more official?
Was it expected?

Has anyone close retired for good e.g. husband, parents?

Was this expected?

What changes did it bring? e.g. financial,
routine changes, etc?

Or has anyone separated from or divorced their husband or wife?

Were you involved at all?

Did you expect it to happen?

What about your brothers or sisters?

D.

FOR ANY DIVORCE/SEPARATION INVOLVING S:

Reasons.

Preparation; anticipation.

Who left? What circumstances.

Forced to leave.

Anyone else involved.

'Alternative' relationship by either spouse.

Finance/housing.

Custody.

Children - their reactions etc.

Clean break/pestering/violence.

Family's reaction.

Legal advice. When.

Maintenance arrangements.

Often seen now.

Anyone started school or college e.g. begun school for 1st time?

Gone away to University?

How did you feel about this?

Has anyone taken any important examinations or qualifications?

What were the results?

SECTION III - LEISURE AND INTERACTION

Have you made any new friends, of either sex, at all?

ASK ABOUT NEW OPPOSITE SEX RELATIONSHIPS.

Have you lost someone you were close to - either because they've moved away, or died, or just drifted apart?

ESTABLISH WHY. IF LOSS OF BOYFRIEND, PROBE ABOUT WHAT HAS HAPPENED TO HIM SINCE THEN.

IF RELEVANT - ANY PROBLEMS WITH SEX, UNRELIABILITY OF PARTNER CONTRACEPTION.

Have there been any big changes in the amount you see of your friends or relatives?

ASK IF APPROPRIATE:

Do you have a boyfriend at all?

FOR SINGLE, SEPARATED OR WIDOWED SUBJECTS: (USE TACT!)

Have you thought of getting engaged or married?
i.e. in the last year or to someone in past years.

How long ago was this? Do you have any regrets about it now?
What happened?

Would you like to get married, do you think?

ASK EVERYONE:

Have there been just the ... of you at home during the time since ... (e.g. AUGUST 1985)?

Has anyone come to stay?

IF YES: For how long?

Was that how long you expected them to stay?

Has anyone left the household at all?

IF YES: Permanently?

Is there anyone you see much less of?

IF YES: Why is this? Do you miss them?

What difference has it made to you?

Have there been any changes in the way you spend your leisure time?

Do you feel that you have enough leisure time?

IF YES: Are there things you'd like to do, but can't?
Why is this, e.g. short of money, transport,
babysitters, etc?

Do you invite friends home at all?

Have you had any difficulties with friends?
Or been worried about them?

Have you had a holiday since ... (e.g. 'AUGUST 85')?

IF YES: How did it work out?
Did you have a good time?
Did anything unexpected or important happen when
you were away..... or on your return?

SECTION IV - HOUSING

Have you moved since... (e.g. AUGUST, 1985)?

E.

FOR ANY RESIDENCE CHANGE EVENT, PROBE:

Why did you move? What happened?
Decision to move.
Were there any difficulties?
Have there been any since then?
Expense.
Consequences.
Did you feel cut off? Baby-minders etc.
New friends.
Impact on job.
Problems re house/neighbours etc.

How long have you lived in your present home?

Do you own it yourself?

IF NOT: ESTABLISH TYPE OF HOUSING. PROBE FOR SECURITY OF
TENURE.

Do you like living in your present house/flat?

Can you tell me if any of the following have been a problem?

Have you got enough room?

IF NOT ALREADY KNOWN, OBTAIN NUMBER OF ROOMS, EXCLUDING BATHROOM.
KITCHEN = 1, IF BIG ENOUGH TO HAVE MEAL IN.

Sharing facilities? Self-contained?

Do you feel it's private enough?

ASK ABOUT SHARING BEDROOMS IN FLAT-SHARES.

Trouble with repairing the house etc?

Anything wrong with roof...
..... dry rot..... damp walls..... rats, etc.

ASK ABOUT PROBLEMS WITH GETTING IT DONE, PAYMENTS ETC.

Have you approached the landlord/Council
about this?

What about facilities for the children playing?

Have there been any problems with the landlord?

Any restrictions?
..... that sort of thing?

ASK WHERE RELEVANT: Does this affect you?

Have there been any problems, that you know of, about paying
for the house, keeping up with the rent/mortgage?

What about with others in the flat/house? How do you get
on?

Any difficulties?

What about the neighbourhood? How do you get on with the
neighbours?

Have there been any difficulties with them?
Have you fallen out with any neighbours in the
flat/house?
What about noise in the house/neighbourhood?
Does it affect you?

Have you ever felt cut off in your present home - too far from friends or work/school?

Have you considered living anywhere else?

IF YES: What have you done about it?

IF RELEVANT, PROBE UNCERTAINTY OF E.G. MOVING, OR LIKELIHOOD OF LEAVING HOME.

Do you or your family have a telephone? A car?
Do you drive?

SECTION V - EMPLOYMENT AND SCHOOL

F.

IF ANY IMPORTANT CHANGE ESTABLISHED,
FIND OUT:

How came about, whose decision.
Financial implications.
Convenience, hours etc.

IF FOR S:

Travel, babysitting/
arrangements for children.
Responsibility/demandingness.
Interest; importance.
Plans for future.

A. FOR SUBJECT:

Do you enjoy your job/school/college?

Has anything happened at work/school/college?

Have you been off work/off school/college at all?

Or put onto a new job/course, or changed job/courses?

Any promotions?

Has anyone you worked with closely left in this time since ...?

IF YES, PROBE:

Seen regularly and frequently at work.
Extra-work involvement/ seen out of work hours?
Close relationship required by job?
Effect on subject's job?
Extent of separation.

How do you get on with your workmates/ schoolmates/ collegemates?

Have you had any trouble or difficulties with them?

Were there any other difficulties at work/school/college?

PROBE FOR EVENTS OR LONG TERM DIFFICULTIES

Long hours, low pay, travel,
short-term or temporary contracts, etc.

What do you like about your job/school/college?
Is there anything you don't like about it?

Promotion prospects.
Responsibility.
Wages.

Is there another work/school/course that you would have liked better?

IF YES: Why?

Have you felt that the demands made on you at work/ school/ college were too great?

Deadlines to meet.
Not enough training/information.
Bad physical conditions.
Moving from job to job if a temporary employee.

Have there been any times in your work/at school/college when you didn't know what was expected of you?

For instance when one person wants you to do one thing
and someone else wants you to do something different?

e.g. supervisors/teachers, colleagues/fellow pupils,
juniors.

IF THERE ARE ANY DIFFICULTIES:

Have you ever thought of asking to be
transferred to another section/department/class?

Have you been expecting any changes in your job/at school/
college?

Are you a member of a trade union?
Do you get proper sick pay when ill?

How do you feel about the future, do you think you'll stay in this
job/ until the end of school/ college?

Might you leave for any reason?

*** REFER TO BOX 'F' (PAGE 12) ***

IF RELEVANT, ASK FOR THREAT OF HAVING TO GIVE UP WORK FOR
ANY REASON.

How important is it for you to do well in this job/ course?

IF RELEVANT, ASK ABOUT UNCERTAINTY OF:

Chances of promotion,
or graduation,
time duration of promotion,
or of student or trainee role.

Have you done different types of work in the past?

Have you ever in your life had to give up a job, or been
dismissed from a job?

DO NOT FORGET THAT STUDENTS ALSO OCCASIONALLY HAVE SATURDAY/
PART-TIME JOBS WHICH MAY BE THROWING UP EVENTS AND DIFFICULTIES
AS WELL AS THEIR SCHOOL/COLLEGE.

B. IDENTIFY CRUCIAL WAGE-EARNER IN HOUSEHOLD (if not S).

Has your husband/boyfriend/father (crucial wage earner) been
working all this last 12 months?

WORK HISTORY FOR LAST 12 MONTHS:

Why left, when arranged, etc.
Any time off through sickness/
redundancy / strike?
Preparation
Chances of new job. What kind.
Impact on home life - actual/likely.
Impact on S's household.

Has had any promotion in the job?

Does have any problems in the job at all?

Is he/she a trade union member?
If your husband/boyfriend/father lost his job, how easy
would he find it to get another?
Has he/she any qualifications or special skills?

C. OTHER IMPORTANT HOUSEHOLD MEMBERS.

Has been off work at all in this time?

COLLECT PERIODS OF UNEMPLOYMENT LASTING 4 WEEKS OR MORE.

SECTION VI - FINANCIAL

Have you had any money worries in the time since...(e.g. 'AUGUST 1985')?

Have you had to borrow off anyone?

GET DETAILS OF DEBTS OR LOANS

Does anyone borrow money from you?

Have you gone without things you really needed?

Are you (or have you been) receiving social security or unemployment benefit?

Any problems with state benefits?

Have you got into arrears?

Rent, gas, electricity, rates.

How much do you owe?

Have any of the services been cut off?

Any letters threatening you with eviction or taking you to court?

Have you had any difficulties with credit facilities at all?

Anything repossessed by hire purchase companies?

What about any problems with health insurance?

Do you have a life insurance at all?

Did you have to cut down on anything in that time?

SECTION VII - MARITAL

(INCLUDES COHABITEE AND SERIOUS BOYFRIEND)

FOR THOSE MARRIED/COHABITING:

Have you and your husband/boyfriend both been living at home during this time?

IF YES:

So you've not been separated for any length of time during this time?

Have either of you ever considered a permanent separation or divorce?

When? Why?

*** IF RELEVANT REFER TO 'BOX 'D' (PAGE 8) ***

How well would you say you and your husband/boyfriend get on in general?

Would you say there are any problems about your relationship?

Has anything happened that has made you feel differently about the relationship?

How often do you and he/she have quarrels or tiffs?

Have there been any serious quarrels since....(e.g. AUGUST, 1985)

IF YES:

What are they usually about?

e.g. disagreement about marriage, money etc.

What happens during a quarrel?

Is there any shouting or throwing things?

Does either of you hit the other?

IF YES:

Has there been any injuries?

What happened?

Has this happened before?

Do you feel you can talk to him quite easily?

Do you talk to him/her about things that worry you?

Do you wish you could confide more in him?

Has this changed since.... (e.g. AUGUST, 1985)

When he has problems or worries does he talk them over with you?

Is your husband/boyfriend and affectionate person.... is he demonstrative?

Do you like doing the same things when you are together?

How do your parents get on with him?

And your family?

And what about his parents - do you get on with them?

PROBE FOR ANY TENSION, EG CULTURAL DIFFERENCES

What about the sexual side of things - have there been any difficulties or problems about this?

Do you ever refuse to have sex?

IF YES: Has this created any problems?

Has he ever forced you to have sex?

What happened?

Any problems with contraception?

IF RELEVANT: ASK ABOUT 'UNPROTECTED SEX'.

As you know in some relationships one of the partners sometimes gets involved with another person, has that ever happened to either of you?

IF PARTNER: When?

How did you first find out about it?

How did things work out?

Does he still ever see that person?

IF S: When was that?

Did your husband/boyfriend find out?

How did things work out?

FOR DIVORCED AND REMARRIED WOMEN WHERE RELEVANT ASK:

Do you ever have contact with your ex-husband?

Have there been any difficulties with him over this?

Any legal or custody problems?

FOR SINGLE MOTHERS ASK:

Continued relationship with husband.

Problems with children e.g. behavioural,
in relation to husband.

Stigma.

Loneliness.

Sexual relationships with men

Financial hardship.

Practical help with childcare (school holidays,
babysitting, illness).

FOR WOMEN LIVING ALONE: ASK ABOUT ANY SEXUAL RELATIONSHIPS SINCE
... (e.g. AUGUST, 1985).

Any problems e.g. fidelity, sex, unreliability partner?

SECTION VIII - INTERACTION WITH PARENTS AND OTHER RELATIVES

How well do you get on with your parents?

FOR S'S MOTHER: (TO BE REPEATED LATER FOR FATHER, SIBLINGS)

A. IF OUTSIDE THE HOUSEHOLD:

Have there been any changes in how you get on/the amount you see of your mother/or how you feel about her since... (e.g. 'AUGUST, 1985')?

IF YES: What difference has this made to you?

B. FOR ALL:

Would you say there's been any tension or difficulty between the two of you?

Do you avoid her....or try to keep out of her way?

Have you felt you could confide in her?

IF YES: Do you find it helpful to talk things over with her?

IF NO: Would you like to be able to confide more in her?
Has this changed?

C. FOR THOSE LIVING WITH MOTHER:

Have you felt that you had to tell your mother about things you do?

For example, do you feel you must tell her where you're going - or if something happens to you like a rise in pay?

Does she like to have a big say in your life - e.g. about the clothes you wear, and your friends, and where you go out?

PROBE FOR INTERFERENCE

IF RELEVANT:

What about your school work - did she put you under much pressure about that?

What about compared to your brothers/sisters/cousins?

Does she often compare you with other people of your age whom she knows - like her friends' children?

Did she have her own plans about your future or is she leaving it up to you?

How do you feel about this?

REPEAT ABOVE QUESTIONS FOR FATHER,
AND FOR EACH SIBLING OR OTHER RELATIVE WITH WHOM RESPONDENT
LIVED DURING THE STUDY PERIOD.

ASK FOR EVERYONE:

How would you say your parents have got on together?
Are there any difficulties between them?

Did/do they quarrel at all - or have periods of not speaking to each other?

Have they worried you at all?

SECTION IX: CHILDREN (IF RELEVANT)

How would you say you get on with your children in general?

Do you ever have quarrels, or are they quite easy?

IF CHILDREN YOUNG: Any problems over baby-minding? PROBE FOR TENSION ETC WITH NANNIES.

IF CHILDREN OLDER: How are they getting on at school?

Do you ever worry about the friends they keep company with or the things they might get up to in their spare time?

Any worries about them smoking, taking drugs?
Or stealing?
Or about sex?
Or about anything like that?

Have you discovered anything about them that has surprised or shocked you?

IF RELEVANT:

Are you happy about their boyfriends/girlfriends?

IF ANY DISABILITY AND NOT COVERED EARLIER IN CHILD'S HEATH -
SECTION I (PAGE 4).

SECTION X - CRISES

G.

FOR ANY COURT APPEARANCE EVENT:

Nature of offence.
First time done it.
First time in court.
Other convictions.
Verdict. Sentence.
Financial implications.
What have other people said?
What have they said at work?
Driving affected (if licence lost etc).
Implications re other people involved.
Were you afraid they would try to get
their own back?

H.

FOR ANY BURGLARY OR LOSS OR DAMAGE TO PROPERTY:

How did it come about? (S's 'fault'?)
Did you see the burglar?
How much was taken?
Problems with insurance.
Anything irreplaceable.
House damaged.

In the time since ... (e.g. 'AUGUST 1985'), has there been any
crisis/emergency?

Any crisis involving your husband/children/parents/brothers/
sisters, etc.?

Has there been anything in the home?

Such as a burglary or fire?

Or being attacked in the street?

Has that ever happened to you?

Or have you ever been sexually approached by anyone against your will?

IF YES: What happened?
Were you hurt?
Were the police involved?

Have you had to break any bad news to anyone?

Have there been any legal troubles, or having to go to court?

Contact with a solicitor?

IF YES: What about?
What happened?

Have you or anyone in the family had any involvement with the police or courts or prison at all?

IF YES: What about?
What happened?

Or any contact with any social agency.... social worker.....
....welfare officer.... marriage guidance counsel.... probation officer?

What about your brothers or sisters, parents, children, friends?

Have any of your relatives had any crises or troubles with which you've had to help.... e.g. has anyone gone to stay with an ill relative?

Or any in which you've been involved?

What about friends?

Have there been any troubles or difficulties concerning them in the past year you've not already mentioned?

MENTION EACH OF CLOSE TIES BY NAME

Have you lost any pets?

IF LOSS OR 'DAMAGE' TO PET, ASK:

How long have you had it?

How did it happen?

Did you see it? (PROBE FOR GUILT)

Have you thought about getting another?

IF RELEVANT: (FOR 'FOREIGNERS')

Have you had any problems connected with living in this country rather than at home?

PROBE FOR IMMIGRANT VISAS, NATURALISATION OR CHANGE OF NAME.

Sometimes people learn unexpected things about others close to them, such as discovering that their child has been stealing at school, or that their husband/wife has been having an affair, or their boyfriend/girlfriend has been seeing someone else. Have you had anything like this?

News that shook you at all?

Anything like that that made you change your idea of a person's character?

Seeing something in a newspaper which shocked you about something personal?

SECTION XI - FORECASTS

Have you or any member of the family had unexpected news in the time since ... (e.g. 'AUGUST, 1985') about anything that has happened or is going to happen?

For example, sometimes a family will get a letter saying they are going to be re-housed.... or they might perhaps get notification of redundancy.

Anything like that?

GIVE TIME TO THINK.

REFER TO POSSIBLY RELEVANT EVENTS ALREADY ESTABLISHED.

SECTION XII - GENERAL

I have asked a good many questions about changes in the period since ... (e.g. AUGUST 1985) - have there been any changes of any importance to you that you've not mentioned?

Has anything particularly disappointing happened during that time that you haven't mentioned already?
.... like a child failing an exam?

Have you had to make any important decisions over this time?

You will have gathered by now that we're interested in anything upsetting, important or exciting that has happened to you....
exciting in a pleasant or unpleasant way.
Has anything given you special pleasure?

IF YES: A visit from a relative.
 Meeting someone.
 A holiday.
 A child winning a prize.
 A present, a new car, etc.

Anything turned out better than expected?
 Financial windfall?
 Relationships improving in some way?

Now this is a bit of an odd question I'm afraid, but we do ask everyone:

Is there anything about yourself you feel self-conscious about?
.... Your appearance?
.... The way you do things?
.... Anything like that?

In your life so far: Are there things you wish had turned out differently?
Or any regrets you have?
.... Over education, training?
.... Over marriage?

[END OF SCHEDULE]

Appendix 8

LIFE EVENTS SCHEDULE: E RECORD

Summary description & threat

CLASSIFICATION - A

0. EDUCATION

- 0 Selection interviews
- 1 Starting/leaving school/university/ courses
- 2 Exams/results
- 3 Other crises (excl. conduct probs & referrals)

1 WORK

- 10 Job interviews/rejectns
- 11 Start job (1st/new/resume)
- 12 Time off sick/ maternity/ strikes >4 wks
- 13 Promotion/demotion/ structural change or prob
- 14 Work relationship crises
- 15 Redundancy/dismissal
- 16 Retirement/giving up wk
- 17 Solicitor/court/ tribunal re work

2 REPRODUCTN (TO 2 WKS AFTER BIRTH)

- 20 Infertility
- 21 Pregnancy
- 22 Complications preg
- 23 Miscarriage
- 24 Induced abortion
- 25 Birth
- 26 Stillbirth
- 27 Contraceptn/sterilisn

3 HOUSING

- 30 Rent paym/threat eviction
- 31 Rented housing event
- 32 Buying/selling house
- 33 Residence change
- 34 Other crises eg neighbs

4 MONEY/POSSESSIONS

- 40 Financial crises/debts
- 41 Financial gains
- 42 Loss, damage, threat to property (excl theft)
- 43 Financial obligation
- 44 Solicitor re possessions

5 CRIME/LEGAL

- 50 Offence against person (mugging, rape, assault)
- 51 Offence against property (theft, burglary, vandalism)
- 52 Other offence (drugs, drive)
- 53 Police contact (not 50-2)
- 54 Court case/inquest/prison (incl s's release)

SUBJECT ID

ID _____

EVENT NO.

E1 _____

DATE OF EVENT

E2a

DD MM YY

RANGE OF UNCERTAINTY OF DATE (total period in weeks)

E2b

6 HEALTH/TREATMNT/ACCIDENTS

- 60 Accident
- 61 Accident + hospital
- 62 Physical illness
- 63 Physical illness+hospital
- 64 Operation
- 65 Suicide attempt
- 66 Psycholog referral/ substance misuse/ child guidance/psychiat disorder
- 67 Hospital discharge
- 68 Solicitor re health

7 MARITAL/PARTNER RELATNSHIP

- 70 1st sexual intercourse
- 71 New reln./resuming one
- 72 S engagement/marriage
- 73 Start cohabitation
- 74 Increase/decrease interaction
- 75 Crisis/breakdown in reln
- 76 Violence/rape - partner
- 77 Separation/divorce
- 78 Solicitor-divorce/custody

8 OTHER RELNSHIPS incl CHILD

- 80 Increase/dec interaction/
- 81 Arrival/depart household
- 82 Engagement/marriage/cohabtn divorce of other
- 83 Child conduct/ truancy/ delinquency
- 84 Crisis breakdown reln
- 85 Break bad news-close tie
- 86 Violence/pestering by relative/key tie
- 87 Contact police/solicitor social worker re above

9 MISCELLANEOUS (INCL PETS)

AND DEATH

- 90 Meeting key person/learn -ing key fact about past
- 91 Break bad news-to less close tie
- 92 Ceremonies
- 93 Pet events
- 94 Other miscell crises
- 95 Death/bereavement

E3a _____

CLASSIFICATION - B
TEMPORAL STATUS OF EVENT

Whether the event involves actual change/occurrence of event or is of a more cognitive nature and prior (as with decisions or forecast) or later in time (as with news, revelation or disclosure).

0. Decision by S to do something
1. Forecast of change to come
2. News that change has happened
3. Revelation (by other to S)
4. Disclosure (by S to other)
5. Actual change (none of above)

E3b _____

ILLNESS RELATED STATUS OF EVENT

Extent to which event is related to actual episode of depression (or relevant dependent variable).

All events rated 1-3 should be excluded from onset analyses

0. Not illness related (most events)
1. Possibly illness related (no actual evidence)
2. Definitely illness related, but to previous episode
3. Definitely illness related, current episode

E4a _____

INDEPENDENCE OF EVENT

Extent to which the occurrence of the event is likely to be independent of any hypothetical presence of disorder.

Independent

- [1. Totally independent
- [2. Nearly totally independent
- [3. Possible influence from S, but unlikely
- [4. Independent, involves S's physical illness

- [5. Compliance of S with external situation

Possibly

independent

- [6. Intentional act by S
- [7. Probable negligence/carelessness on S's part
- [8. Arguments/tension, end contact
- [9. End contact, no argument
- [10. S's love/sex events
- [11. Partner's love/sex events

E4b _____

FOCUS

Extent to which the event is focussed on S or on others

- S focussed [1. Subject focussed
[2. Joint focussed with other(s)

- 0 focussed [3. Focussed on a possession or pet
[4. Focussed on another person(s)

E5 _____

THREAT/UNPLEASANTNESS OF EVENT

The degree of unpleasantness i.e. ongoing negative feelings associated with the event, and threat i.e. uncertainty and anticipation of difficult consequences associated with the event.

1. Marked threat/unpleasantness
2. Moderate threat/unpleasantness
3. Some threat/unpleasantness
4. Little/no threat/unpleasantness

A. SHORT-TERM

Threat/unpleasantness, rate peak in first few days after start of event

CONTEXTUAL

Interviewer judgment based on all relevant factual information

E6 _____

REPORTED

S's response to event and style of reporting it

E7 _____

B. LONG-TERM

Threat/unpleasantness, rate peak in 10-14 days after start of event

CONTEXTUAL

E8 _____

REPORTED

E9 _____

NEW CLASSIFICATION OF THREAT (a/b)

If event is 2 on long-term contextual threat and S or J focussed, then rate 'a' or 'b':

1. Upper moderate threat (a)
2. Lower moderate threat (b)
- 1. Not a 2S or J event

E10 _____

CONTAMINATION OF THREAT BY S's COPING

The extent to which S's immediate reactions had an impact on the long-term contextual threat

0. No contamination

1. Possibly] S reduced the threat (from '1 or 2' to '3' or below),
2. Probably]
3. Possibly] S increased the threat (from '3' or '4' to '2' or above)
4. Probably]

E11 _____

DATE OF NEUTRALISATION OF EVENT

Give date at which severe event is neutralised/reduced in threat to 3 or 4.

-1 N/A: event never severe, or not neutralised

E12 _____
DD MM YY

RELATIONSHIP BEFORE EVENT
(of other to S)

- | | |
|--|--|
| -1. No other involved | |
| 0. Parent | 6. Confidant (if not above) |
| 1. Child | 7. Ex-partner |
| 2. Spouse/cohabitee | 8. Other friend/neighbour/ workmate |
| 3. Girl/boyfriend | 9. Causal acquaintance/ stranger |
| 4. Sibling | 10. Key person from past |
| 5. Other relative/ spouse's relatives | |

E13 _____

RATE OF CONTACT BEFORE EVENT

- | | |
|-------------------------------|---|
| -1 Only S. involved | |
| 0. Household member | 4. Seen monthly or more |
| 1. Seen daily/weekdays | 5. Seen 6 monthly or more |
| 2. Seen weekly or more | 6. Seen once per year |
| 3. Seen two-weekly or more | 7. Seen less than once per year/never before |

DESCRIBE EVENT

E14 _____

ADDITIONAL EVENT DIMENSIONS - SEVERE EVENTS OR 2-OTHER FOCUSED
EVENTS ONLY

Rate these scales for events rated '1-marked' or '2-moderate' on
long-term contextual threat .

Most scales: 1: marked
 2: moderate
 3: Some
 4: Little/none

1. Loss

The amount of loss for S involved in the event (e.g. by death or separation from other, or material possessions, employment or loss of 'cherished idea').

Contextual

E15 _____

2. Irreversibility of loss

The possibility that the loss (recorded above) can be regained.

-1 No loss rated

1. Irreversible loss (e.g. deaths, definite loss of cherished idea)
2. Less irreversible loss
3. Distinct possibility of lost object being restored.

E16 _____

3. DANGER

a) Potential future loss

The degree of unpleasantness of a specific future crisis that might seem to most people likely to occur as part of the aftermath of the event, and the likelihood of such a crisis (e.g. potential loss by death or separation, potential loss of employment, material possessions, health or miscellaneous potential losses).

1-4

Contextual

E17 _____

4. Inevitability of danger

This scale reflects whether the danger recorded in the scales above is inevitable or not.

-1. No danger rated

1. The anticipated event is almost certainly inevitable.
2. Anticipated outcome less inevitable.

E18 _____

BEFRIENDING PROJECT

5. Humiliation/entrapment

1. Humiliation: separation
2. Humiliation - other's delinquency
3. Humiliation: put down
4. Entrapment
5. Death
6. Separation - subject initiated
7. Other key loss
8. Lesser loss
9. Danger alone*

Optional 3 extra points

10. Humiliation: separation/
trapped = 1+4
11. Humiliation: other's delinquency/trapped
= 2 + 4
12. Humiliation: put down/
trapped = 3+4

E19 _____

6. Matching 'D' event

Does the event match a prior difficulty of 1-3 level of severity
(excluding purely health difficulties) present for 6 months
continuously

If yes: give difficulty number:

If no: rate -1

difficulty no.

E20A _____

difficulty no.

E20B _____

7. Fresh Start complex

0. None
1. Delogjamming but not 2 or 3.
2. Potential Fresh Start
3. Fresh Start
4. Fresh-start - Reconciliation
5. Rewarding status change only.

E21 _____

SHORTENED LIFE EVENTS

SUBJECT'S ID _____

Write all events (in brief), referring to long LEDS schedule for rating codings
possible rate in order of occurrence, using back of sheet for extra longhand description

[illegible]

345

STUDY OF THE EXPERIENCES OF PATIENT'S RELATIVES BEFORE AND AFTER HOSPITAL: RELATIVES INFORMATION DOCUMENT

As you know, your relative has recently been seen at the Maudsley/Bethlem Hospital for their mental health problems. Our hospital is well known for its research in this area and we are particularly keen to find out as much as possible about things that contribute to mental disturbance. We think people's experiences are especially significant, but we need to find out exactly what is important about them. We hope this will lead to better treatment and services for patients and their relatives. The study is being carried out by Professor Paul Bebbington (Consultant Psychiatrist), Dr. Elizabeth Kuipers (Consultant Clinical Psychologist) and David Raune (Researcher in Psychology).

Your relative has agreed to take part in this research study and has given us permission to ask you if you would also be willing to take part. By asking you about how things were at home before your relative came in to hospital, and by asking them about their experiences, we hope to learn more in order to help improve services for patients and their relatives. David Raune would like to speak to you for two hours, using a questionnaire, in order to ask you some questions about how things were at home before your relative came into hospital. Nine months after this he would like speak to you again in order find out how things have been since then.

Anything you say would not be told to your relative and would be treated in the strictest confidence. Permission will be asked to audio-tape some of what you say so that more of it can be remembered afterwards by David Raune. The information we obtain from you will eventually be recorded on a computer but your name will not be used. If you would like, after the study is finished, we can send you information about what we have learned from it and how we think health services might be improved in the future for new patients.

Participation in the study is **entirely voluntary** and if you decide not to take part this will not affect in any way the care your relative receives from the hospital. If you are willing to take part you are free to withdraw from the study at any time without having to say why. It would be very helpful if you would agree to be a part of this study so that your experiences can go toward making the patients and their relatives services better.

If would like to ask any questions or want find out anything else at all please telephone David Raune on 0171-703 5411 Extension 3491, who will be happy to speak to you. He is based in:-

*The Social Psychiatry Section
12 Windsor Walk
Denmark Hill
London
SE5 8AF*

Appendix 10

STUDY OF THE EXPERIENCES OF PATIENT'S RELATIVES
BEFORE AND AFTER HOSPITAL ADMISSION:
RELATIVES CONSENT FORM

I am signing here to say that I would be willing to take part in this study looking at patient's relatives experiences before and after hospital admission.

Signed:

Name in Block letters:

Dated:

Witnessed By:

Name in Block letters:

Dated:

Thank you very much for your participation in this study. Your help is greatly appreciated.

Appendix 11

RELATIVE SOCIO-DEMOGRAPHIC FORM

* = database

Relative's name:

* Relative's code number [RICN]:

* Relative's patients code number [RIPCEN]:

Relative's patients number:

* Sex: [RSDSEX]

Male = 1 / Female = 2

Title: Mr / Ms / Mrs /

Date of Birth: [PSDDOB]

* Age [RSDAGE]:

1= male 2= female

Address:

Telephone Number:

* Living with a partener [RSDLWP] :

1=Yes / 2= No

* Marital Status [RSDMS] : 1= single / 2= married / 3= seperated / 4 =divorced / 5= widowed / 6= partener / 7 = other

* Ethnic Origin [RSDEO]: 1= European -White / 2= Black - Caribbean / 3= Black African / 4= Indian / 5= Chineese / 6= Other

* Employment Status [RSDDES] : 1= unemployed / 2= retired / 3= student/ 4= part - time / 5= full-time

***** Occupation [RSDO] :

* Relationship to patient [RSDRTP]: 1= parent / 2= grandparent / 3= sibling / 4=other relative / 5=partener / 6=friend /

* Living with patient for at least 3 months before admission [RSDLWPBA] : 1= Yes / 2= No

* Number of children living with before onset [RSDNCLW] :

* Household composition before onset [RSDHCBA]: 1= carer patient other adults / 2= carer patient / 3= carer other adults / 4= carer

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* Number of hours face to face contact [RSDFTFC] :

* EE SCORES

EE STATUS [EESTATUS] =

1= high 2 = low

H [REEH] =

0= No Hostility / 1=Present as Generalisation Only / 2= Present as Rejection Only / 3= Present as Generalisation and Rejection=

CC[REECC] =

EOI [REEEOI] =

0= None / 1= Very Little / 2=Some / 3=Moderately high / 4= High / 5= Marked

W [REEW]=

P [REEPR] =

Appendix 12

CAMBERWELL FAMILY INTERVIEW SCHEDULE

From the original abbreviated version, Vaughn and Leff (1976)
(E. Moore, 1991)

MRC Social Psychiatry Unit/Institute of Psychiatry
London SE5

Hospital:

Ward:

Date admitted:

Community Psychiatric Nurse:

Date of interview:

Primary informant:

Interviewer:

Patient: 1. Male 2. Female

Household:

- | | |
|-----------------------|----------------------|
| 1. Marital | 5. Married Sibling |
| 2. Parental (Mo+Fa) | 6. Unmarried Sibling |
| 3. Parental (Mo only) | 7. Adult child |
| 4. Parental (Fa only) | 8. Other relatives |

BACKGROUND INFORMATION

Composition of household: N.B. patient first

| NAME | REL. TO X | AGE | SEX | EDUC. /EMPLOY |
|------|-----------|-----|-----|---------------|
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |
| 5. | | | | |
| 6. | | | | |
| 7. | | | | |
| 8. | | | | |
| 9. | | | | |
| 10. | | | | |

EMPLOYMENT DETAILS OF FAMILY MEMBERS

N.B. Patient first:

| FAM. MEMBER | TYPE OF JOB | HRS. /WEEK |
|-------------|-------------|------------|
| 1. | | |
| 2. | | |
| 3. | | |
| 4. | | |
| 5. | | |
| 6. | | |
| 7. | | |
| 8. | | |

PSYCHIATRIC HISTORY

Can we start by thinking about when the trouble/X's problems first began?

When did you first notice anything unusual about X's behaviour?

How was X's behaviour?

What happened?

How did you feel about it?

Was it sudden or gradual?

Were there times when X seemed his/her normal self?

What about the current episode/most recent time?

How did you/X come to contact the hospital this time?

When did it begin to get worse?

Probes:

How did it show itself?

What did you/X do?

Who was involved in making arrangements to come to the hospital/admission?

Were there any difficulties?

TIME BUDGET

I'd like to get a picture of how X usually spends a weekday. Take a typical day - what time would X get up... etc.?

| | Weekday | Weekend |
|-----------------------------------|---------|---------|
| Get up? | | |
| Breakfast? | | |
| Leave for work/spend the morning? | | |
| Have lunch? | | |
| Spend the afternoon? | | |
| Have tea/supper? | | |
| Spend the evening? | | |
| Go to bed? | | |

Hours per week in face-to-face contact with primary informant: _____

IRRITABILITY

One of the ways this kind of trouble can affect people is to make them more irritable - perhaps more likely to feel bothered by things that wouldn't normally worry them.

Has X been irritable in the last month?

With you?

With other members of the household?

When did it last occur?

Can you describe what happened?

What did you do?

Probes:

Has X been more likely to shout, lose his/her temper, been impatient etc.?

What sort of things make X like this?

How often has X been this way?

Are there certain things that make him/her worse?

Does it happen at a certain time of day?

Who is often/was present?

How do you cope with this irritability?

Can you make a difference to it/control it at all?

How?

Has X's irritability changed since the trouble started? Has it changed with regard to any one person in particular?

If more severe irritability mentioned first:

Apart from the sort of thing you've just mentioned, have there been any other times when you've felt 'niggled' but which perhaps didn't develop into an argument?

If Denial:

Has X not been cross at all?

Has X lost his/her temper in the last year?

QUARRELS

Most families have arguments from time to time. Has X had any rows/quarrels recently?

With you? ... anyone else?

Can you describe what led up to it?

What happened?

How long did the disagreement last?

Has X ever left home as long as overnight because of a quarrel?

NAGGING AND GRUMBLING

Do you find you ever feel the need to grumble - or moan - at X?

Probes:

What sort of things do you complain about?

What might you say?

How often?

Does anyone else in the house grumble at X?

GETTING ALONG TOGETHER

You have already told me a lot about how you get along together with X.
Is X generally a friendly person?

Can you get close to him/her?

What is X like to spend time with?

Does X ever get on your nerves?

Have you tended to keep out of each other's way at all in the last couple of months?

Are there any ways in which you'd like X to be different?

Have you found that you feel differently about X since this trouble began?
(if yes: have you found that you have behaved differently towards X as a result?)

Has X behaved any differently towards you since the trouble started?

Has the amount of affection you feel for X changed at all?

Do you feel his/her interest in you has altered?

Probe:

Are you satisfied with the amount of affection or interest X shows in you?

How would you like things to be different?

How do you feel about the change?

Does it bother you?

ATTITUDE TO ILLNESS

What do you think has made X like this ... or how he/she was when they were admitted the last time?

Do you think X could do more to control his/her ... (specify) ?

SYMPTOMS AND BEHAVIOUR PROBLEMS

I'd like to ask some questions about the way X might have been affected by this trouble. I have a list of behaviours which people we have seen before have experienced. Many might not apply to X - but if we run through them quickly perhaps you could tell me whether or not X has been like this. Can we concentrate on the last three months?

N.B. PROBES: How often? How much of the time?
Where/when did it happen?
How did those present react?
Did it make you feel tense/on edge?
How did you deal with it?

Bodily functions

1. What has X's sleep been like?
Any problems getting off to sleep?
Nightmares?
Early waking?
2. Has X's appetite been affected?
Has X not wanted to eat?
3. Has X complained of headaches/dizziness?
Any other pains?

Underactivity

UNDERACTIVITY ☐

4. Has X been lacking in energy?
Has X tended to sit/lie around and not do a great deal?
Has X stopped doing the things he/she normally does?

SLOWNESS ☐

5. Has X been taking longer than usual to do things?
like - dressing; washing the dishes, etc.

Overactivity

OVERACTIVITY / RESTLESSNESS ☐

6. Has X had times of being unusually cheerful/ excited /agitated?
What sort of thing has made you notice this?
Has X been restless and paced around a lot?
Has X been more talkative than usual? (sworn more/ been more rude)?

CONCENTRATION ☐

Aggressive/destructive Behaviour

DESTRUCTIVE BEHAVIOUR ☐

7. Has X been aggressive?
Has X hit out or been threatening?
Can you tell me what happened?

8. Has X been destructive with things about the house?

INAPPROPRIATE SEXUAL BEHAVIOUR ☐

- ① WITHDRAWING THE INITIATIVE ☐
- ② CONVERSATION INCOHERENCE ☐
- ③ CONVERSATION EDDITY IN APPROPRIATENESS ☐
- ④ SOCIAL MIXING & ABILITY TO MAKE CONTACTS APPROPY ☐
- Withdrawal
- ⑤ SOCIAL MIXING & HOSTILE SOCIAL CONTACTS ☐
9. Has X kept to himself a lot? ☐ SOCIAL MIXING?
- Has he/she not wanted to meet people?
- Has he/she tended to avoid anyone? ATTENTION SEEKING
- What about relatives/friends that come to the house? BEHAVIOUR ☐

Has X had times of being less talkative?

Will X answer when people speak to him/her?

Have X's activities been limited by this - has it meant that X couldn't go out?

Memory Loss

10. Has X had any marked difficulties with memory?
- like not being able to find his/her way home?
- forgetting names/addresses?
- seemed confused?
- Has this meant that X has been unable to go out?

Fears and anxiety

⑥ PANIC ATTACKS AND PHOBIAS

11. Has X expressed any unusual fears?
- Had periods of anxiety or panic?
- Had special fears - such as not wanting to go out?
- does it occur at specific times?
- does it mean X cannot go out alone?
- is X limited in any other way?
- Does X talk about these fears at all?
- to whom?

Worrying

- ⑦ SUICIDAL AND SELF HARMING IDEAS AND BEHAVIOUR ☐
12. Has X been worrying a lot about things?
- anything in particular?
- what makes you think that he/she is worried/worrying?
- does X talk about these things?

⑧ DEPRESSION ☐

Depression

13. Has X seemed very miserable/depressed/low in mood?
- tearful?
- said that life was not worth living?
- what do you think makes X feel this way?
14. Has X ever tried to harm him/herself - or to take his/her life?
- Have you felt worried that he/she might do so?

Obsessions

15. Has X been unusually fussy or finicky about anything?
- like being very concerned about germs/cleanliness
- Has X taken to doing things in only a certain way - following a specific routine?
- Does X repeat the same action over and over again - like washing

his/her hands or checking that the door is locked?

Personal Care

(13) SOCIALLY UNACCEPTABLE HABITS OR MANNERS
(17) PERSONAL APPEARANCE AND HYGIENE ☐

16. Has X looked after himself all right?

does X keep fairly clean and tidy?

(does X seem odd in appearance?/rock/shuffle/slur/jumble words?)

Delusions/hallucinations

17. Has X seemed unusually jealous of anyone?

Has X expressed any strange ideas about ... you (others in household)?

Does X feel that people are against him/her? - in what way?

Has X accused you of doing something that you haven't done?

Did X do anything strange connected with these ideas?

18. Has X talked/laughed to him/herself at all?

What have you said to him/her about these things?

Did you do anything?

Bizarre Behaviour

(10) LAUGHING AND TALKING TO SELF ☐
(11) ACTING OUT OF BIZARRE IDEAS ☐
(12) POSTURING AND MANNERISMS ☐

19. Has X done anything else which seemed odd or unusual for him/her?

like wandering off from home?

anything about his/her behaviour which seemed different from his/her usual self?

Drinking/Gambling

20. Has X been drinking/gambling at all?

HOUSEHOLD TASKS

Can I ask about the various jobs that have to be done in the family? What do you think X should do about the house, given that he/she is working/isn't working at the moment?

Has the amount X has done in the way of helping to do household chores changed at all since the trouble began?

Does X regularly do any of the following jobs? (how often? etc.)

Washing the pots/dishes?

Shopping?

Cleaning?

Washing/laundrying own clothes?

Preparing food: for self/for others?

Dealing with household maintenance (eg. repairs)?

Are you satisfied with the way X tackles/completes a task?

What about money matters?

Does X have any responsibility for bills etc.?

Has there been any change in X's ability to deal with these things?

SUMMARY

What difference has X's admission/ recent trouble made to you and the family?

From your own (informant's) point of view, what has been the most disturbing aspect of your son's/daughter's/X's trouble?

(2) BEHAVIORS NOT OTHERWISE SPECIFIED
THAT IMPAIDE PROGRESS

EXPERIENCE OF CAREGIVING INVENTORY

The following pages contain a number of statements that commonly apply to persons who care for relatives or friends with a serious mental illness.

We would like you to read each one and decide how often it has applied to you over the past one month.

If it has never happened or rarely happened you would CIRCLE the number 0 or 1. If it has happened sometimes, then you would CIRCLE the number 2. If it has happened often or seems to have happened nearly always, then you would CIRCLE the number 3 or 4.

It is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. While there seem to be a lot of statements, you will find that it won't take more than a moment or so to answer each one.

Male version

Experience of Caregiving Inventory (ECI) 1994

*G Szmukler, P Burgess, H Herrman, A Benson, S Coiusa, S Bloch
University of Melbourne, Victoria, Australia*

During the past month how often have you thought about:

0 = never
1 = rarely
2 = sometimes
3 = often
4 = nearly always

PLEASE CIRCLE

- | | | |
|-----|--|-----------|
| 1. | your covering up his illness | 0 1 2 3 4 |
| 2. | feeling unable to tell anyone of the illness | 0 1 2 3 4 |
| 3. | his difficulty looking after money | 0 1 2 3 4 |
| 4. | having to support him | 0 1 2 3 4 |
| 5. | what sort of life he might have had | 0 1 2 3 4 |
| 6. | his risk of committing suicide | 0 1 2 3 4 |
| | | |
| 7. | I have learnt more about myself | 0 1 2 3 4 |
| 8. | I have contributed to others understanding of the illness . . . | 0 1 2 3 4 |
| 9. | being unable to do the things you want to do | 0 1 2 3 4 |
| 10. | how health professionals do not take you seriously | 0 1 2 3 4 |
| 11. | his dependence on you | 0 1 2 3 4 |
| 12. | helping him to fill in the day | 0 1 2 3 4 |
| | | |
| 13. | I have contributed to his wellbeing | 0 1 2 3 4 |
| 14. | that he makes a valuable contribution the the household . . . | 0 1 2 3 4 |
| 15. | the effect on your finances if he becomes more seriously ill . | 0 1 2 3 4 |
| 16. | dealing with psychiatrists | 0 1 2 3 4 |
| 17. | him always being at the back of your mind | 0 1 2 3 4 |
| 18. | whether you have done something to make him ill | 0 1 2 3 4 |
| | | |
| 19. | that he has shown strengths in coping with his illness | 0 1 2 3 4 |
| 20. | I have become more confident in dealing with others | 0 1 2 3 4 |
| 21. | how family members do not understand your situation | 0 1 2 3 4 |
| 22. | that he is good company | 0 1 2 3 4 |
| 23. | I have become more understanding of others with problems . | 0 1 2 3 4 |
| 24. | how he thinks a lot about death | 0 1 2 3 4 |
| | | |
| 25. | his lost opportunities | 0 1 2 3 4 |
| 26. | how to deal with mental health professionals | 0 1 2 3 4 |
| 27. | feeling unable to have visitors at home | 0 1 2 3 4 |
| 28. | how he gets on with other family members | 0 1 2 3 4 |
| 29. | backing him up when he runs out of money | 0 1 2 3 4 |
| 30. | how family members do not understand the illness | 0 1 2 3 4 |
| | | |
| 31. | how he deliberately attempts to harm himself | 0 1 2 3 4 |
| 32. | I have become closer to some of my family | 0 1 2 3 4 |
| 33. | I have become closer to friends | 0 1 2 3 4 |
| 34. | I share some of his interests | 0 1 2 3 4 |
| 35. | I feel useful in my relationship with him | 0 1 2 3 4 |
| 36. | how health professionals do not understand your situation . . | 0 1 2 3 4 |

During the past month how often have you thought about:

- 0 = never
1 = rarely
2 = sometimes
3 = often
4 = nearly always

PLEASE CIRCLE

37. whether he will ever get well

38. feeling the stigma of having a mentally ill relative

39. how to explain his illness to others

40. others leaving home because of the effect of the illness

41. setting him up in accommodation

42. how to make complaints about his care

43. I have met helpful people

44. I have discovered strengths in myself

45. feeling unable to leave him home alone

46. the effect of the illness on children in the family

47. the illness causing a family breakup

48. him keeping bad company

49. how his illness effects special family events

50. finding out how hospitals or mental health services work

51. doctors knowledge of the services available to families

52. the difficulty getting information about his illness
- 0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

During the past month how often have you thought about him being:

53. moody

54. unpredictable

54. withdrawn

56. uncommunicative

57. not interested

58. slow at doing things

59. unreliable about doing things

60. indecisive

61. irritable

62. inconsiderate

63. behaving in a reckless way

64. suspicious

65. embarrassing in appearance

66. behaving in a strange way
- 0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

0 1 2 3 4

COPE INVENTORY

(Dr. C. S. Carver, Dr. J.K. Weintraub and Dr. M.F. Scheier (1989))

When a person has a mental health difficulty this can cause members of their family stress and problems. This questionnaire asks you to show how you have *typically* tried to deal with problems that you have experienced due to your relative having a mental health difficulty. Below are a list of things you may have done. Please decide if you have used each strategy since your relative became ill, and if so, how often you have used it. "1" means you have *never* done it 2 means you have *rarely* done it, 3 means you have *sometimes* used it and 4 means you have used it *a lot*. There are no right or wrong answers. Please treat each question separately.

- 1 = I have never done this
 2 = I have rarely done this
 3 = I have sometimes done this
 4 = I have done this a lot

HOW OFTEN HAVE YOU:-**PLEASE CIRCLE**

- | | | | | |
|---|---|---|---|---|
| 1. Gone to the cinema or watched TV, to think about the problem less | 1 | 2 | 3 | 4 |
| 2. Drank alcohol or took drugs in order to think about the problem less | 1 | 2 | 3 | 4 |
| 3. Sought God's help | 1 | 2 | 3 | 4 |
| 4. Talked to someone about how you felt | 1 | 2 | 3 | 4 |
| 5. Made a plan of action | 1 | 2 | 3 | 4 |
| 6. Put aside other activities in order to concentrate on the problem | 1 | 2 | 3 | 4 |
| 7. Looked for something good in what was happening | 1 | 2 | 3 | 4 |
| 8. Made fun of the problem | 1 | 2 | 3 | 4 |
| 9. Pretended the problem hadn't really happened | 1 | 2 | 3 | 4 |
| 10. Given up your attempts to get what you wanted | 1 | 2 | 3 | 4 |
| 11. Let your feelings out about the problem | 1 | 2 | 3 | 4 |

- 1 = I have never done this
 2 = I have rarely done this
 3 = I have sometimes done this
 4 = I have done this a lot

HOW OFTEN HAVE YOU:-

PLEASE CIRCLE

- | | |
|---|---------------|
| 12. Taken alcohol or drugs to help you get through the problem | 1 2 3 4 |
| 13. Turned to work or other substitute activities to take your mind off the problem | 1 2 3 4 |
| 14. Tried to find comfort in your religion | 1 2 3 4 |
| 15. Just gave up trying to solve the problem | 1 2 3 4 |
| 16. Made jokes about the problem | 1 2 3 4 |
| 17. Learned to live with the problem | 1 2 3 4 |
| 18. Forced yourself to wait for the right time to do something about the problem | 1 2 3 4 |
| 19. Taken additional action to try and get rid of the problem | 1 2 3 4 |
| 20. Kept yourself from getting distracted by other things | 1 2 3 4 |
| 21. Made sure you did not make matters worse by acting too soon | 1 2 3 4 |
| 22. Asked people who have had similar experiences what they did | 1 2 3 4 |
| 23. Tried to see the problem in a different light, to make it seem more positive | 1 2 3 4 |
| 24. Tried to get emotional support from friends or relatives | 1 2 3 4 |
| 25. Accepted that the problem had happened and that nothing could be done to change it | 1 2 3 4 |
| 26. Got upset and let your emotions out | 1 2 3 4 |
| 27. Refused to believe the problem had happened | 1 2 3 4 |
| 28. Tried to get advice from someone about what to do | 1 2 3 4 |
| 29. Tried to come up with a strategy about what to do | 1 2 3 4 |
| 30. Concentrated your efforts on doing something about the problem | 1 2 3 4 |

Social Functioning Scale (SFS)*

*(Printed with the kind permission of Dr Max Birchwood)

Name _____ Date _____

SUMMARY OF SCORES

| Sub-Section | Transformed Scores |
|---------------------------|--------------------|
| Social Withdrawal | _____ |
| Interpersonal Functioning | _____ |
| Prosocial Activities | _____ |
| Recreation | _____ |
| Level of Independence | _____ |
| Competence | _____ |
| Performance | _____ |
| Employment | _____ |
| Total Score (Mean) | _____ |

SECTION ONE: WITHDRAWAL

Part One

1. What time does (s)he get up each day?
- Average weekday
- Average weekend (if different)
- 3 < 9 am
2 9 am to 11 am
1 11 am to 1 pm
0 > 1 pm
2. How many hours of the waking day does (s)he spend alone?
(e.g. on own in room, walking out alone, listening to radio or watching TV alone, etc.)?
Count the number of hours in an average day spent alone and tick (V) one of the following.
- Hours spent alone
- | | | | |
|------|-------------------------------|-----|---|
| 0-3 | Very little time spent alone. | (V) | 3 |
| 3-6 | Some of the time. | - | 2 |
| 6-9 | Quite a lot of the time. | - | 1 |
| 9-12 | A great deal of time. | - | 0 |
| 12- | Practically all the time. | - | |
3. How often will (s)he start a conversation at home?
- 0 1 2 3
Almost never / rarely / sometimes / often (underline)
4. How often will (s)he leave the house (for any reason)?
- 0 1 2 3
Almost never / rarely / sometimes / often (underline)
5. How does (s)he react to the presence of strangers?
- 0 1 2 3
Avoids them / feels nervous / accepts them / likes them (underline)

Appendix 15

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INTERPERSONAL FUNCTIONING

Part Two

1. How many friends does (s)he have at the moment?
(persons whom (s)he will see regularly, do activities with, etc.)

Number of friends

2. Has (s)he someone (s)he finds it easy to discuss feelings and difficulties with?

3 0
YES/NO

3. How often has (s)he confided in them?

0 1 2 3

Almost never / rarely / sometimes / often

4. Do other people discuss their problems with him/her?

0 1 2 3

Almost never / rarely / sometimes / often

5. Does (s)he have a boy/girl-friend? (If not married)
(If married = 3)

3 0
YES/NO

6. Has (s)he had any arguments with friends, relatives or neighbours recently?

3 2 1 0

None / 1 or 2 minor / continued minor or 1 major / many major

7. How often are you able to carry out a sensible or rational conversation with him/her?

0 1 2 3

Almost never / rarely / sometimes / often

8. How easy or difficult does (s)he find it talking to people at the moment?

3 2 2 0 0

Very easy / quite easy / average / quite difficult / very difficult

9. Does (s)he feel uneasy with groups of people?

3 2 1 0

Almost never / rarely / sometimes / often

10. Does (s)he out of preference spend time on his/her own?

0 1 2 3

Often / sometimes / rarely / almost never

PRO-SOCIAL ACTIVITIES

Part Three

Put a tick (✓) in the appropriate column to show how often (s)he has participated in any of the following activities over the past three months

0 1 2 3

| | Never | Rarely | Sometimes | Often |
|---|-------|--------|-----------|-------|
| Cinema | | | | |
| Theatre/concert, etc. | | | | |
| Watching an indoor sport (e.g. squash, table-tennis) | | | | |
| Watching an outdoor sport (e.g. football, rugby) | | | | |
| Art gallery/Museum. | | | | |
| Exhibition | | | | |
| Visiting places of interest | | | | |
| Meeting, talk, etc. | | | | |
| Evening class. | | | | |

Continued

| | 0 | 1 | 1 | 3 |
|---|-------|--------|-----------|-------|
| | Never | Rarely | Sometimes | Often |
| Visiting relatives in their homes | | | | |
| Being visited by relative | | | | |
| Visiting friends (including boy/girlfriend) | | | | |
| Being visited by friends (including boy/girlfriend) | | | | |
| Parties | | | | |
| Formal occasions | | | | |
| Disco, etc. | | | | |
| Night club/social club | | | | |
| Playing an outdoor sport | | | | |
| Club/society | | | | |
| Pub | | | | |
| Eating out | | | | |
| Church activity | | | | |
| Any other activity? | | | | |
| | | | | |
| | | | | |
| | | | | |

Rarely Sometimes Often

| | | |
|--|--|--|
| | | |
| | | |
| | | |

SECTION TWO: RECREATION ACTIVITIES

Please place a tick in the appropriate column to indicate how often (s)he has done any of the following activities over the past 3 months

| | 0 | 1 | 2 | 3 |
|--|-------|--------|-----------|-------|
| | Never | Rarely | Sometimes | Often |
| Playing musical instruments | | | | |
| Sewing, knitting | | | | |
| Gardening | | | | |
| Reading things | | | | |
| Watching television | | | | |
| Listening to records or radio | | | | |
| Cooking | | | | |
| DIY activities | | | | |
| Fixing things (car, bike, household, etc.) | | | | |
| Walking/rambling | | | | |
| Driving/cycling (as a recreation) | | | | |
| Swimming | | | | |
| Hobby (e.g. collecting things) | | | | |
| Shopping | | | | |
| Artistic activity (painting, crafts, etc.) | | | | |
| Any other recreation or pastime? | | | | |
| | | | | |
| | | | | |
| | | | | |

Rarely Sometimes Often
1 2 3

| | | |
|--|--|--|
| | | |
| | | |
| | | |

SECTION THREE: INDEPENDENCE (C)

Please place a tick against each item to show how able (s)he is at doing or using the following

| | 3 | 2 | 1 | 0 |
|---------------------------------------|-------------------------|---------------------------------|---|--------------|
| | Adequately (no help) | Needs help (or prompting) | Unable (or without lots of help) | Not known |
| Public transport | | | | |
| Handling money correctly | | | | |
| Budgeting | | | | |
| Cooking for self | | | | |
| Weekly shopping | | | | |
| How to look for a job | | | | |
| Washing own clothes | | | | |
| Personal hygiene | | | | |
| Washing, tidying, etc. | | | | |
| Purchasing from shops | | | | |
| Leaving the house alone | | | | |
| Choosing and buying own clothes | | | | |
| Taking care of personal appearance | | | | |

Independence (P)

Please place a tick against each item to show how often (s)he has done the following over the past three months.

| | 0 | 1 | 2 | 3 |
|---|-------|--------|-----------|-------|
| | Never | Rarely | Sometimes | Often |
| Buying items from shops alone (without help) | | | | |
| Washing pots, tidying up, etc. | | | | |
| Regular washing, bathing, etc. | | | | |
| Washing own clothes | | | | |
| Looking for a job (if unemployed) | | | | |
| Doing the food shopping | | | | |
| Prepare and cook a meal | | | | |
| Leaving the house alone | | | | |
| Using buses, trains, etc. | | | | |
| Using money | | | | |
| Budgeting | | | | |
| Choosing and buying clothes for self | | | | |
| Takes care of personal appearance | | | | |

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SECTION FOUR: EMPLOYMENT

1. Is (s)he in regular employment (including industrial therapy, rehabilitation or re-training courses)?

Yes / No (underline)

If yes: What sort of job? _____

How many hours does (s)he work each week? _____

How long has (s)he had this job? _____

If no: When was (s)he last in employment? _____

What sort of job was it? _____

How many hours per week? _____

2. If not employed:

Is (s)he registered disabled? Yes / No (underline)

Does (s)he attend hospital as a day-patient? Yes / No (underline)

Do you think (s)he is capable of some sort of employment?
Definitely yes / would have difficulty / definitely no

How often does (s)he make attempts to find a job (e.g. go to Job Centre, look in newspaper, etc.)?
Almost never / rarely / sometimes / often

3. If not employed:

How does (s)he usually occupy his/her day?

Morning: _____

Afternoon: _____

Evening: _____

SOCIAL ADJUSTMENT SCALES
SCALED SCORE EQUIVALENT OF RAW SCORES
MEAN: 100 S.D.: 15
SCALED SCORES

RAW SCORES

| SCALE SCORE | With-drawal | Inter-action | Pro-social | Rec-reation | Independ-ence (p) | Independ-ence (c) | Occupational |
|-------------|-------------|--------------|------------|-------------|-------------------|-------------------|--------------|
| 0 | 57.5 | 55 | 65.0 | 57.0 | | | 81.5 |
| 1 | 65.0 | 78 | 76.0 | 63.0 | 53.0 | | 89.5 |
| 2 | 70.5 | 86 | 79.0 | 66.0 | 56.5 | | 95.0 |
| 3 | 75.5 | 91 | 83.0 | 69.0 | 60.0 | | 97.5 |
| 4 | 80.0 | 96 | 86.0 | 72.0 | 63.5 | | 103.0 |
| 5 | 84.0 | 100 | 88.5 | 74.5 | 67.5 | | 107.0 |
| 6 | 87.5 | 105 | 91.0 | 77.0 | 70.0 | | 109.5 |
| 7 | 90.5 | 111 | 93.5 | 80.0 | 71.5 | | 112.5 |
| 8 | 93.5 | 124 | 95.0 | 81.5 | 73.5 | | 114.0 |
| 9 | 96.5 | 145 | 96.5 | 84.0 | 75.0 | | 116.0 |
| 10 | 100.0 | | 98.0 | 86.5 | 76.5 | 55.0 | 122.5 |
| 11 | 104.5 | | 100.0 | 89.0 | 78.0 | 58.0 | |
| 12 | 110.0 | | 101.5 | 91.0 | 79.0 | 61.0 | |
| 13 | 116.5 | | 103.0 | 93.5 | 80.0 | 64.0 | |
| 14 | 124.5 | | 105.0 | 96.0 | 81.5 | 66.5 | |
| 15 | 133.0 | | 107.0 | 98.0 | 83.0 | 69.0 | |
| 16 | | | 108.5 | 101.0 | 84.5 | 72.5 | |
| 17 | | | 110.0 | 103.0 | 85.5 | 75.0 | |
| 18 | | | 111.5 | 105.5 | 87.5 | 76.5 | |
| 19 | | | 112.5 | 108.5 | 89.0 | 78.0 | |
| 20 | | | 114.5 | 110.5 | 90.5 | 79.5 | |
| 21 | | | 116.0 | 113.0 | 92.0 | 81.5 | |
| 22 | | | 117.5 | 116.5 | 94.0 | 83.0 | |
| 23 | | | 119.0 | 119.0 | 97.0 | 84.5 | |
| 24 | | | 121.0 | 121.5 | 100.5 | 86.5 | |
| 25 | | | 123.0 | 124.5 | 103.5 | 88.5 | |
| 26 | | | 124.0 | 126.5 | 105.5 | 90.5 | |
| 27 | | | 125.0 | 129.0 | 106.5 | 91.5 | |
| 28 | | | 126.0 | 131.0 | 107.0 | 93.0 | |
| 29 | | | 127.0 | 133.0 | 108.0 | 94.5 | |
| 30 | | | 128.0 | 135.0 | 109.0 | 95.5 | |
| 31 | | | 129.0 | 137.0 | 110.0 | 96.5 | |
| 32 | | | 129.5 | 139.0 | 112.5 | 97.5 | |
| 33 | | | 130.0 | 140.0 | 114.5 | 100.5 | |
| 34 | | | 130.5 | 142.0 | 116.5 | 103.5 | |
| 35 | | | 131.0 | 144.0 | 118.5 | 107.0 | |
| 36 | | | 131.5 | 145.0 | 121.5 | 110.0 | |
| 37 | | | 132.0 | | 124.0 | 114.0 | |
| 38 | | | 132.5 | | 127.0 | 117.5 | |
| 39 | | | 133.0 | | 131.0 | 125.0 | |
| 40 | | | 133.5 | | | | |
| 41 | | | 134.0 | | | | |
| 42 | | | 135.0 | | | | |
| 43 | | | 136.0 | | | | |
| 44 | | | 137.0 | | | | |

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Appendix 16

SCAN 1.1 (WHO, 1992, p. 130) DEFINITION OF A DELUSION

Four necessary but not sufficient characteristics of a delusion:

- (i) The belief is described clearly in the respondent's own words, not simply assented to following a leading question.
- (ii) It is held with a basic and compelling subjective conviction, though the degree of certainty may fluctuate or be concealed.
- (iii) It is not susceptible, or only briefly, to modification by experience or evidence that contradicts it; ie it is incorrigible.
- (iv) The belief is impossible, incredible or false (often called 'bizarre').

Exclusion criteria are also part of the SCAN operationalisation, and these involve rules about social, cultural, religious and political beliefs, overvalued ideas and induced beliefs.

Appendix 17

EXAMPLES OF THEMES IN DELUSIONS

(A) DELUSIONS

Reference

0010) My house was bugged and I was on the radio

0038) the things in the room were set up to pose questions to me. e.g. the way the phone cable and toilet lids were positioned.

Persecutory

0014) (S is mixed race): I thought they were going to tar and feather me and burn my skin off.

0004) the IRA want to kill me because of my plan to unite the world in peace.

Depressive

0009) my insides are rotting, my abdominals have been removed, I am going to die from the sexually transmitted disease

0037) I thought I would murder my family with a knife. I didn't want to.

Grandiose

0016) I could make contact with John Lennon....he said play it cool. I am telepathic..can communicate with flies.. I told it to crawl onto my finger, than told it to fly off.

0006) I hold a world record in cross country running.

Appendix 18

EXAMPLES OF TYPES OF STRESSFUL EVENTS

DANGER

0049) Patient is a trainee chef. She has an episode of psoriasis. Last time it happened it lasted for one year.

0053) Patient's mother has a triple heart by-pass operation

LOSS

0032) Patient is made redundant from the bank she has worked in for 4 years. She did want a career there. No implication of personal failing as others are also being made redundant.

0022) Patient's aunt, whom he is close to, dies of cancer.

SELF-ESTEEM

See examples listed in Chapter 7.

HUMILIATION

0053) Patient realises she may be infertile.

0029) Patient's husband physically assaults her, says she is an ugly bitch and leaves, saying he is not coming back.

INTRUSIVE

See examples listed in Chapter 7.

Appendix 19

PLACES WHERE PARTICIPANTS WERE RECRUITED FROM

Maudsley/Bethlem

Wards

Emergency Clinic

Eileen Skellern ward 1

Eileen Skellern ward 2

Eileen Skellern ward 3

Douglas Bennet ward 2

Dennis Hill unit

Aubrey Lewis ward 3

Jim Birley unit

Community Teams

Peckham community mental health team

Norwood community mental health team

Camberwell North community mental health team

Camberwell South community mental health team

Nunhead community mental health team

Brixton community mental health team

Croydon

Warlingham Park Hospital

Farley Male ward

Farley Female ward

Barbera House

Alice House

PLACES WHERE PARTICIPANTS WERE RECRUITED FROM / Cont'd..

May Day Hospital

Woodcote ward

Croydon Community Teams

South West Croydon community mental health team

South East Croydon community mental health team

North East Croydon community mental health team

North West Croydon community mental health team

North North Croydon community mental health team

Central East Croydon community mental health team

Central West Croydon community mental health team

Appendix 20

Publication Arising From This Thesis:

Kuipers, E. and Raune, D.J. (1999). The early development of Expressed Emotion and burden in the families of first onset psychosis. In Birchwood, M. and Jackson C. (eds), Early Intervention for Psychosis, Wiley.

Papers Presented of the Data from this Thesis:

Raune, D., Kuipers, E. and Bebbington, P. (1999). Psychosocial stress and the themes in first episode psychosis delusions and verbal auditory hallucinations. Presented at the Third International Conference on Psychological Treatments for Schizophrenia, University of Oxford, England, 24/9/99.

Raune, D., Kuipers, E. and Bebbington, P. (1999). The differences between high and low expressed emotion caring situations at first episode psychosis. Presented at the International Society for the Psychological Treatments of Schizophrenia and other Psychoses, U.K. Chapter Conference, University of Essex, England 16/9/99.

Kuipers, E. and Raune, D. (1997). The development of expressed emotion and burden in carers at first onset psychosis: preliminary data. Presented at the First International Conference on Early Intervention for Psychosis, Stratford upon Avon, England, 6/7/97.

The early development of Expressed Emotion (EE) and Burden in the families of first onset psychosis

Elizabeth Kuipers & David Raune

April 1998

"I find myself asking for God to take it from her and give it to me. If I could do anything to take it from her I would prefer that" (Mother of 19 year old daughter).

"I was so shocked. If I had been that type of person I would have had a heart attack" (father of 23 year old son).

"Emotionally I couldn't handle it, it was just tearing me apart". (Mother of 19 year old son).

As can be seen from the above quotations, the impact on carers of those with first onset psychosis, and the implications for the care involved, cannot be minimised. First onset is a unique opportunity to look at these processes in families, both to compare them with what we know from research on more long term groups, to help understand how family reactions are formed and then develop, and finally to consider optimal intervention at this early stage, before attitudes have hardened and rejection, resignation or despair set in. The purpose of this chapter is to address these issues, using data from previous research on long term families and some new data on first onset psychosis.

The Impact of Care

We know from previous research that the impact of having to offer care to a relative with psychosis is likely to be severe. Since the 1950's researchers have looked at this area and arrived at a fairly consistent consensus on the burden that the caring role imposes on relatives and on the range and depth of the areas that are affected. (Fadden et al. 1987; Kuipers 1993). This burden has been defined most succinctly as the "effect of the patient on the family" (Goldberg & Huxley, 1980). Carers do not choose these roles; they find that they become carers, often in the long term, because of changes in a close relative, who develops psychosis. These changes are usually poorly understood, the person's behaviour often misattributed (Brewin et al. 1991) as "laziness" or "being difficult". It is often extremely difficult to access appropriate help, because the person with psychosis will frequently not agree that there is a problem, as will other professionals at times, and often there has to be quite a severe or dramatic crises before mental health agencies become involved.

The caring role in psychosis frequently requires the carer to take on tasks and roles not normally expected to need supervision in another adult, unless they have a physical disability or dementia. The initial reactions to this can range from bewilderment to denial, anxiety and shock. Most carers will have no idea of what to expect and often make assumptions that this will be an acute and temporary problem which will resolve. Such unrealistic expectations are usually based on lack of information. They include not being aware of the extended time

period often required for social recovery in psychosis, and the likelihood that role performance will be severely impaired during this time. Care givers are likely to be elderly mothers of young adult clients, given the typical age of onset of psychosis (Scazufca & Kuipers, 1997). It is evident that when people take on the role, they are likely to suffer increased levels of worry and strain, and three times the clinical rate of depression and anxiety as the normal population (30% compared to around 10%) (Fadden et al. 1987). They are also likely to be emotionally upset, primarily because of feelings of loss, but also due to a range of other feelings, from anger, frustration, guilt, anxiety about the future, to over concern and overprotection. Carers will themselves suffer from reduced social networks (Andersen et al. 1984) and are likely to feel both isolated and stigmatised. This is because mental illness is still both feared and demonised in our society. Typically, negative symptoms such as social withdrawal are found most difficult to deal with, as is disruptive or embarrassing behaviour when it exists (Creer and Wing 1975; Gibbons et al. 1984).

Thus a carer rapidly finds themselves involved in providing care, with few perceived resources, no specialist knowledge, and often no perceived support from services.

In particular, emotional support is felt to be lacking, even if services can provide practical help (MacCarthy et al. 1989). Thus, despite being an important and much valued resource for those with psychosis, who can enhance recovery (Kuipers & Bebbington, 1985) carers can easily feel both exhausted and

exploited (Noh & Turner, 1987).

Expressed Emotion

The importance of the quality of the relationships that are part of the caring role has also been examined in considerable detail since the 1950's. While carers may be tolerant and understanding of a client's difficulties, the very nature of psychosis tends to mitigate against this. People with psychosis often have unusual or bizarre beliefs (delusions), may hear or see distressing things that are not apparent to others (hallucinations), have jumbled or unusual thought processes (thought disorder) and suffer from severe levels of apathy, self neglect or social withdrawal (negative symptoms). They themselves may not agree that there is a problem (poor insight) and may not want to discuss how they are feeling (suspiciousness). All these symptoms typically appear in young adulthood when the individual may also be trying out new relationships, be involved in substance abuse (drugs or alcohol), and starting new and independent lifestyles with all the attendant stresses and demands that these imply. Thus carers are particularly likely to attribute at least some of the symptoms, particularly negative ones, to adolescence, the drug culture, unsuitable friends, or general stress. A typical reaction at this stage, is to feel angry or frustrated at what is perceived to be unmotivated or odd behaviour, and to try to change this by becoming annoyed or critical. An alternative response, particularly in the acute stages of a florid attack, is to 'take over' care and every day tasks, in order to protect and look after the individual, who may be perceived

correctly as no longer competent. While perfectly understandable, and useful in the acute stage, this overprotective response quickly becomes over involved and intrusive in the recovery stage, when acute symptoms have improved, as it can prevent the adult being able to take back appropriate roles and functioning in the future.

These two coping styles, criticism (critical comments [CC]) and emotional over involvement (EOI) are the key predictive features of Expressed Emotion [EE].

This has now been reliably measured in a wide variety of studies, and found in a range of diagnoses, not just schizophrenia and manic depression, to be a reliable predictor of outcome. High levels of either or both CC or EOI, predict poor outcome in the ensuing 9 months after an acute episode, if the person goes back to live in this environment. Typically, around 50% of those returning to live in high EE families will relapse in the next 9 months, compared to 21% returning to low EE environments (Kavanagh 1992; Kuipers, 1994; Bebbington & Kuipers, 1994). These relationships are not restricted to family carers, but also occur in staff, who in key relationships with clients not only find the same behaviour difficult to deal with, (negative symptoms and disruptive behaviour), but show similar, (particularly critical) attitudes towards it (Moore et al. 1992; Kuipers & Moore, 1996).

Links between Burden and Expressed Emotion

Despite the fact that the literature on the impact of care, (burden) in psychosis,

and the literature on Expressed Emotion in carers has existed since the 1950's remarkably few studies have measured them both. Jackson et al. (1990) first completed an exploratory study suggesting that they were linked. Smith et al. (1993) investigated 49 relatives of those with psychosis and found that carers with a high level of EE reported higher levels of disturbed behaviour in clients, more subjective burden and less (perceived) effective coping. Scazufca & Kuipers (1996) looked at 67 relatives (50 key relatives) of 50 clients with psychosis. We found that high EE relatives had significantly higher mean scores for their burden of care than low EE relatives. High EE carers also perceived more deficits in client functioning. In fact, social functioning and symptoms in clients were independent of the EE rating of carers. We also found that relatives who were working were more likely to be low EE, high contact with clients was associated with increased burden and more carers were women. The association between work and low EE was not causal of course, but did suggest that those who worked might also be able to have a different perspective on the problems, because caring was not their only role. It was also clear, in this study, that low EE carers were still burdened, but perceived this as less problematic. We concluded that "the measures of both EE and burden are more dependent on relatives appraisal of the patient's condition than on their actual deficits" (p. 586). Further "that EE is a measure of the quality of the relationship ... viewed through relatives appraisal of the circumstances". (p. 586).

These findings suggest two things. Firstly, that a consideration of burden might make it easier to identify poor outcome families who might benefit from

intervention; secondly, that intervention might be particularly valuable if it was focussed on impaired social functioning, and on how to improve a family's ability to negotiate about it.

First episode studies

Although the research evidence so far appears promising, the effects of these processes are not yet established in first onset psychosis. For instance, studies of early onset schizophrenia have found much weaker effects for the predictive effects of EE. Leff and Brown (1977) found a 38% relapse rate in first admission high EE families, compared to 69% relapse rates in readmission families. MacMillan et al. (1986) in a first episode study, claimed that high EE was not predictive of outcome at all. Stirling et al. (1991) found that family EE at first onset was not predictive of outcome in the first 9 months, although there was some evidence of an association between EE and the psychiatric status of patients at an 18 month follow up (Stirling et al. 1993).

Birchwood and Smith (1987) have posited a transactional model for EE. They have suggested that EE develops over time and that families emerge as high EE, depending on their ability to cope with problems. This has put coping responses as a central feature of high or low EE carer responses.

More recently, attribution research has found that, after intervention, there was a shift to more universal attribution for negative behaviours rather than personal

blame by carers (Brewin, 1994). Bentsen et al. (1998) found that both criticism and hostility were predicted by a patient's lack of employment, more than 3 hospital admissions and difficult behaviour. Bertando et al. (1992) found that high warmth in carers was associated with low admission rates even in high EE families. Thus there seems to be some suggestion that it would be helpful for families to reattribute difficult symptoms, to remain as positive and empathic about the client as possible, and perhaps to intervene before problems become too intractable.

There are thus good reasons to investigate the processes of adaptation to the caring role at first onset in psychosis, when it might be possible to answer the following questions.

1. Is EE a relevant factor at first onset and does it relate to outcome at this stage?
2. Is EE related to carer burden and distress?
3. Is EE associated with particular coping responses, and further are some coping responses more adaptive than others?

There are also theoretical questions to be answered. These include, how EE develops over time, whether it is a transactional process, and how our understanding of the vulnerability stress model of psychosis (Neuchterlein et al.

1992) might become more specific.

Clinically there are several implications. We know from the literature that family interventions in schizophrenia are “an effective and underused treatment” (Anderson and Adams 1996) and have well attested efficacy (Penn and Mueser, 1996). However these have tended to be offered to families with long term problems. We are interested to consider instead whether early intervention could reduce morbidity, distress and outcome for first onset families, how to engage such families in treatment at a stage when shock and denial may be paramount, and finally how best to focus any intervention to meet the needs of this group.

In order to investigate these issues a first onset study was undertaken, and some of the results are included here.

Assessment Instruments

Standard social and demographic data was collected from both patients and carers. Patients were further assessed with the **SCAN 1.1** (WHO 1992) in order to measure and classify their psychopathology and associated behavioural problems.

Carers were also given - **The Social Isolation Scale** (SIS (O'Connor and Brown 1984); carers were asked about the frequency of contact and the quality

of their social ties. **The Camberwell Family Inventory** (CFI) (Vaughn and Leff 1976) was conducted in order to rate EE. The CFI is a semi-structured interview which asks carers about the start of the patients problems, focussing on the previous 3 months, covering how the patient spends their time and how their behaviour has changed. All interviews were tape recorded. A relative was considered high EE if they made six or more critical comments, revealed any hostility or were rated 3 or more on emotional over involvement. In order to assess burden the **Experience of Caregiving Inventory** (Szmukler et al. 1996) was administered. This is a 66 item instrument which asks about the subjective experience of caregiving in 8 areas covering difficult behaviours, negative symptoms, stigma, problems with services, effects on the family, need for back up, dependency and loss and 2 areas of positive experiences of caring, covering positive personal experiences and good aspects of the relationship.

The **Cope** (Carver et al. 1989; 1994) was administered to measure how often carers had been using each coping style when they experienced stress and problems related to the patient. The scales assessed were: *Active Coping, Planning, Seeking Instrumental Social Support, Seeking Emotional Social Support, Suppression of Competing Activities, turning to Religion, Positive re-interpretation and growth, Restraint Coping, Acceptance, Focus on and Venting the Emotions, Denial, Mental Disengagement, Behavioural Disengagement, Alcohol/Drug Disengagement, and Humour*. Finally, carers were given the **Beck Depression Inventory** (BDI) (Beck et al. 1979) and the **General Health Questionnaire** (GHQ-28) (Goldberg and Hillier, 1979) to look at carer morbidity

and stress levels.

Results

There was a 10% refusal rate for patients and a carer refusal rate of 6%. Data was available on 46 key carers and patients.

Patient Sample:

Diagnosis: Most (70%) patients carried a schizophrenia or schizoaffective diagnosis. The remainder carried the diagnoses of Bipolar disorder (13%), or other psychotic disorders (17%). 58% were male and 42% were female. Patients were aged between 17-64 with a median age of 28. 21% were teenagers, half were under 30 and over three quarters (82%) were under 40. As expected, men had an earlier illness onset (means of 28 v 33), although the difference was not statistically significant. As expected for a first episode study, patients had recent onset, with illness lengths ranging from 9 to 2260 days with a median of 19 weeks. Men had a median illness length 10 weeks longer than women. 54% of the sample were white with 17% black Caribbean, 20% black African and 9% other. 24% of the patients lived with a partner and 34% lived alone. Interestingly, nearly a third (32%) of women had made previous psychiatric contact for non-psychotic conditions compared to only 7% of the men. Nearly two-thirds (65%) of patients were unemployed at the time of interview.

CARERS

Carers were mainly a group of **parents** (61% parental, 20% were partners). They were predominantly **middle-aged** (mean age 47), and women (72%), of whom over half (60%) **worked** as well as cared (47% worked full time). About a fifth (21%) were retired and nearly two thirds (61%) had a partner. Over half (54%) lived with the patient and nearly half (46%) were **living with the patient** at illness onset. Carers had moderately high **face to face contact** (27 hours per week mean), with nearly a third (32%) in contact for more than 35 hours per week. Just over half the carers were **white** (56%). At the time of the assessment 44% of patients were **in hospital**. Most (65%) carer assessments were carried out in their home. Nearly a fifth (19%) described **previous experience** of caring for someone with a psychiatric problem.

Carers `Needs`

Carers had a range of needs due to social isolation, distress and depression to burden and less constructive coping styles. Nearly half (41%) of carers lived either alone or just with the patient, with the group on average having `some` isolation on the SIS (score of 3.1; 1 = marked isolation, 4 = none). The mean for the sample as a whole was just above the threshold for mild depression (9.4) with 41% showing at least mild depression. Just over a third (35%) of carers were defined as `cases` by the GHQ (bi-modal score of 6). There was a high (.78) positive correlation between distress and depression total scores, but the

number of hours of face to face contact was not linked to either of these. As a group, carers had on average 6 worries on their mind 'nearly all the time'. Despite this, 7/10 of the most frequent thoughts about aspects of caring were actually about positive experiences. On the other hand one third of the carers were relying on 'a lot' on alcohol or drugs, when they felt stress related to the patient.

Finally, nearly half (44%) of the carers were high EE. 33% were highly critical, 30% hostile and 22% emotionally over involved.

Linked between EE, burden and coping

EE and its components were found in the univariate analysis to be linked to increased subjective burden, carers' coping styles, an increased perception by carers of patients' social functioning deficits. In the multivariate analysis, the strongest link with overall EE and with criticism and hostility was coping style, whereas with EOI the strongest links were social isolation score and not living with a partner. The most consistent and strongest link with EE was avoidant coping in the form of Behavioural Disengagement.

There were quantitative differences between high and low EE carers on the ECI : low EE carers were burdened in all areas, but high EE carers were more burdened. Positive aspects of the caring experience were among those most frequently thought about in both the Low and High EE groups, but *positive*

experiences were not significantly higher in the low EE group.

Coping

There were also differences in coping styles. Both high and low EE carers used all the designated styles, but high EE carers used some styles significantly more. High ratings on all four EE components were linked with behavioural Disengagement and alcohol/drug disengagement.

Carer Perception of Social Functioning

High CC and hostility both linked with SFS total and with the subscales of interpersonal functioning and recreation. High EOI however was not linked with these at all, but was instead linked to withdrawal and the level of independence: competence. Thus, highly critical carers perceived patients as having less interaction and less social success and believed they did not engage much in hobbies and pastimes. High EOI carers, on the other hand, saw patients as more withdrawn and incompetent.

High EE carers were more subjectively burdened than Low EE carers overall. Two areas in which the High EE group scored significantly higher were 'difficult behaviours' and 'Loss'.

High EE carers used behavioural disengagement, mental disengagement,

alcohol/drug disengagement, and 'seeking support for emotional reasons' more frequently than low EE carers.

Finally, High EE carers perceived more deficits in all areas of social functioning, but significantly more so in interpersonal functioning, indicating that they thought of patients as having less interpersonal ability and success.

In summary, overall EE was linked most simply and strongly to coping style in a two variable model. Behavioural Disengagement coping was highly significant, and seeking support for emotional reasons was just significant.

Specific Links with components of EE

A Third of the sample were highly critical. All areas of **Burden** were rated higher in the High CC group, significantly so for overall Burden and the 2 subscales of Difficult Behaviours and Effect on the family. High CC were also linked with **coping style**. Three forms of Avoidant coping were used more frequently by the high CC group: behavioural disengagement, mental disengagement, and alcohol/drug disengagement. Three other types of coping styles were also higher in the high CC group: Restraint, seeking support for emotional reasons, and denial. CC were also linked with overall **perception of social functioning** and the 2 subscales of recreation and interpersonal functioning. The Multivariate analysis revealed that the strongest link with the simplest model for High CC was coping style in the form of behavioural disengagement.

It was also of interest that there was a strong trend for the Burden of negative symptoms to be higher in the high EE group. This is consistent both with attributional theory and previous EE studies.

A third of the carers were Hostile. Hostility was linked to overall **Burden**. Multivariate analysis revealed that the strongest link with hostility was coping style in the form of behavioural disengagement. There was a strong trend ($p=0.08$) for carers to be hostile if **the patient was presenting with a problem for the first time**. 8/24 of the non-Hostile carers had patients who had presented before whereas *none* of the 14 Hostile carers had patients who had presented before. It is possible that carers lowered their expectations about the patient after the previous neurotic problem had emerged.

Just over a fifth (21%) of the carers were highly emotionally over-involved. These carers were more **Burdened** overall, particularly on the subscales of dependency, loss, and problems with services. EOI was linked to avoidant **coping** style, in the forms of behavioural disengagement and alcohol/drug disengagement. It was also linked to the **perceived social functioning** areas of social withdrawal and level of independence or competence, with a strong trend for high EOI carers to have patients less likely to be working or attending rehabilitation activities. All high EOI carers were **women**, 8/10 of them mothers. High EOI carers were also more likely to be in high (more than 35 hours per week) **face to face contact** with their relatives, and to be more socially isolated.

Forty three percent of the sample were already High EE at the first onset with a median illness length before the carer interview of only 19 weeks. This finding is more supportive of a triggering than an emergent model of EE. Since coping was so strongly linked to high EE, some carers may become high EE because of less adaptive coping, particularly avoidant coping. This could be developed as an outcome measure for family interventions.

Conclusion

The main result of the first onset study described here is to replicate previous research on the links between high EE, high subjective burden and avoidant coping responses in carers. The appraisal of some behaviour as problematic seems to lead to high EE responses even at this early stage, and is not restricted to a more chronic course. In the long term, avoidant coping seems a particularly ineffective way to manage these problems, and suggests both a specific avenue for intervention and for measuring outcome. This could mean that dealing with the upset, shock and misunderstanding associated with first onset psychosis is not so different from later reactions in carers. It also suggests that early intervention might be particularly beneficial in reducing depression, stress and distress in carers, and the likelihood of symptoms recurring in the client.

Our results add to our understanding of the particular stresses of caring, which in turn can be stressful for the client. They emphasise the importance of

improving the quality of the relationships that form the environment of people with psychosis. They may well remain vulnerable to future episodes, but can be helped to recover in a supportive setting.

The general importance of negotiated and constructive problem solving in caring environments underlines the value of these interventions, as already described in detail in various published manuals (Anderson, et al. 1986; Falloon 1985; Kuipers et al. 1992; Barraclough and Tarrier 1992).

Summary

Evidence is accumulating that at the time of first onset, psychosis already imposes burdens on family carers who may react in the same way, and find the same sorts of behaviour problematic, as long term carers. The appraisal of problems appears to be a key issue, as does attribution of blame and a tendency to use avoidant coping. The evidence is thus that particular problems trigger appraisal processes that can lead to high perceived burden and high EE. This is counter to the idea that the development of these phenomena is the result of a much more gradual interactive process. Ineffective coping strategies appear to be rapidly triggered in the early stages of dealing with the problems posed by the emergence of psychosis in a relative. Key interventions for this group would seem to be the facilitation of constructive problem solving related to the poor social functioning of the patient, as well as an understanding of the emotional loss and isolation that carers are likely to perceive, which may hinder

engagement with services.

Thus early intervention would seem to be indicated in psychosis as in other severe and disabling conditions. If it was available it might be able to improve adjustment to perceived problems, as well as longer term reductions in distress and morbidity. This might reduce both the emotional and financial costs for carers and their relatives.

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